It's not who you know, It's how you know them

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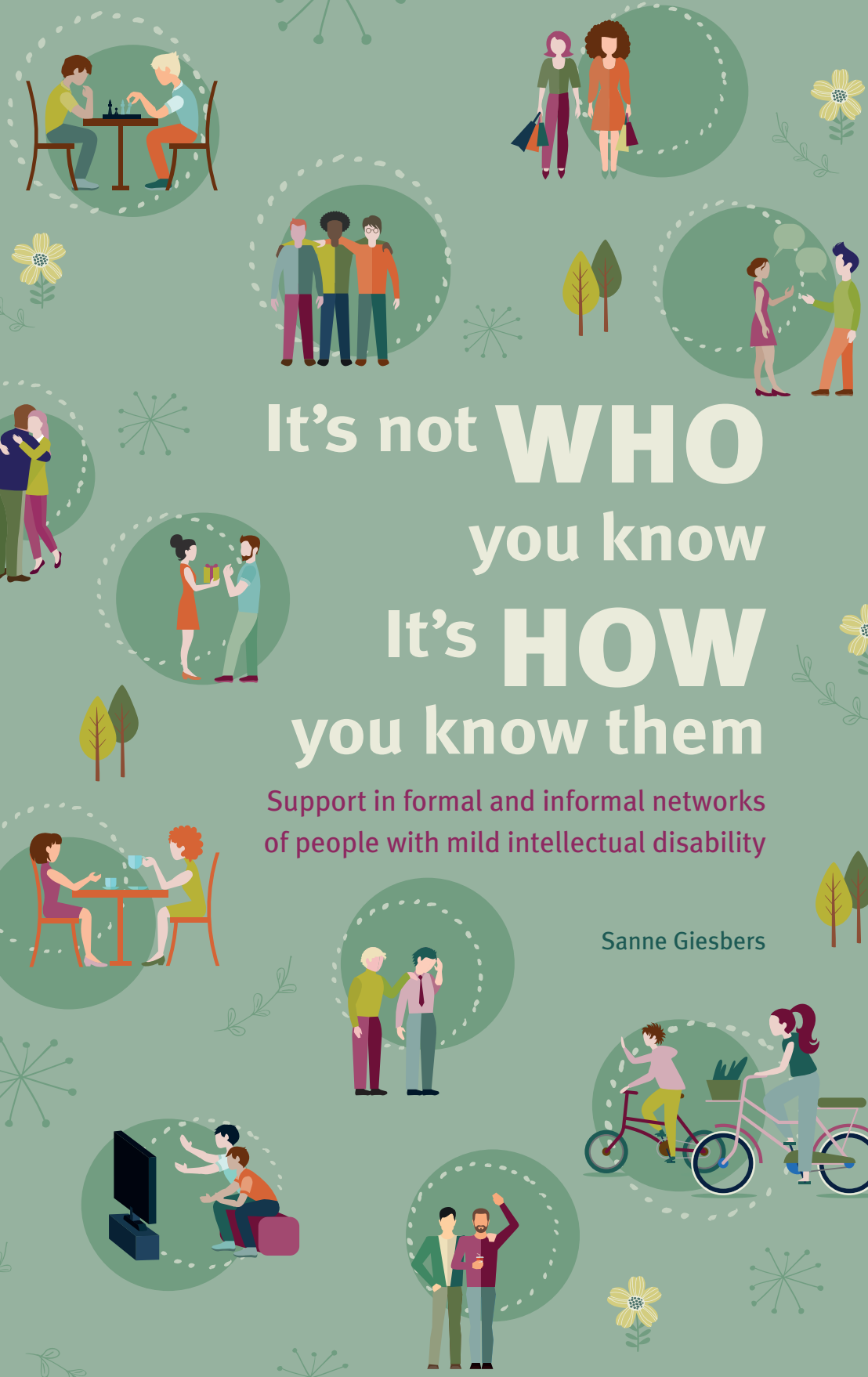
Publication date:
2020

Document Version
Publisher's PDF, also known as Version of record



It's not WHO you know It's HOW you know them

Support in formal and informal networks of people with mild intellectual disability

Sanne Giesbers

It's not **WHO** you know

It's **HOW** you know them

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The research described in this thesis was performed at department Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, the Netherlands. This research was funded by service provider Dichterbij.

Printing of this thesis was financially supported by Tilburg University.

Cover: wenz iD || wenzid.nl
Lay-out: ProefschriftMaken || proefschriftmaken.nl
Printing: ProefschriftMaken || proefschriftmaken.nl

ISBN: 9789082118490

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Proefschrift

ter verkrijging van de graad van doctor aan Tilburg University
op gezag van de rector magnificus, prof. dr. K. Sijtsma,
in het openbaar te verdedigen ten overstaan van een
door het college voor promoties aangewezen commissie
in de Aula van de Universiteit op vrijdag 24 januari 2020 om 13.30 uur

door

Sanne Adriana Hendrina Giesbers
geboren op 11 november 1987 te Nijmegen

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Inclusion is not bringing people into what already exists;
it is making a new space, a better space for everyone

George Dei

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CHAPTER 1

1

General introduction

From Deinstitutionalization to Social Inclusion

Over the last decades, there has been increasing recognition that people with intellectual disability are full citizens with the same rights as non-disabled persons. From the 1970s, the deinstitutionalization of disability services has dominated the policy discourse within western society (Mansell & Beadle-Brown, 2010), and this has been supported by the philosophy advocated by the normalization movement (Bank-Mikkelson, 1980; Nirje, 1970, 1985; Wolfensberger, 1972, 1983). As a result, the number of individuals with intellectual disability living in large institutional settings has been declining in many western countries, with an increasing growth of the number of individuals living at home or in smaller, community-based settings (Alba, Prouty, Scott, & Lakin, 2008; Lakin & Stancliffe, 2007; Mansell, 2006; Tøssebro, 2016).

In the Netherlands, services for people with intellectual disability have joined this international deinstitutionalization movement, though the closure of large institutions has started relatively late (late 1990s) and progressed relatively slowly (European Intellectual Disability Research Network, 2003; Schuurman, 2014; Van Gennep, 1997). Deinstitutionalization in the Netherlands is still ongoing; compared to other countries (e.g., Britain, Canada) the amount of people with intellectual disability supported in residential settings is relatively high (Woittiez, Eggink, Putman, & Ras, 2018). Moreover, the level of participation of people with intellectual disability in society is still behind the level of participation of the general population (Van Hees, Oldenkamp, De Putter, Van der Hoek, & Boeije, 2018).

As the deinstitutionalization movement has gained momentum, research has started to focus on the outcome of this transition for people with intellectual disability. Even though the closure of institutions led to people with intellectual disability living and participating physically in the community (e.g., Bratt & Johnston, 1988), from early on a gap between people with intellectual disability and other community members has been noted (e.g., Edgerton, 1967). That is, people with intellectual disability still had few meaningful relationships with other community members and experienced little sense of actual membership and belonging. As a result, research has shifted from a focus on physical inclusion to also addressing social inclusion. Despite being physically present in the community, people with intellectual disability may still experience social barriers with community members, such as stigma, discrimination, and rejection (Hall, 2005; Jahoda & Markova, 2004, Pelleboer-Gunnink, Van Weeghel, & Embregts, 2019). In line with this recognition, the "Convention on the Rights of Persons with Disabilities" was adopted by the United Nations in 2006 (CRPD; United Nations, 2006). The convention protects the human rights of people with disabilities and aims for "full and effective participation and inclusion in society" of people with disabilities. While the importance

of the social inclusion of people with intellectual disability is now widely acknowledged, Cobigo, Ouellette-Kuntz, Lysaght, and Martin (2012) found a lack of consensus on what constitutes the concept of social inclusion for people with intellectual disability. Based on their conceptual review, they defined social inclusion as: "(1) a series of complex interactions between environmental factors and personal characteristics that provide opportunities to (2) access public goods and services, (3) experience valued and expected social roles of one's choosing based on his/her age, gender, and culture, (4) be recognized as a competent individual and trusted to perform social roles in the community, and (5), belonging to a social network, within which one receives and contributes support (Cobigo et al., 2012, p. 82). Thus, belonging to a supportive social network is one of the key aspects of social inclusion. More specifically, belonging to a socially supportive network is part of social inclusion, but it can also facilitate other components of social inclusion (Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014). For example, interpersonal relationships may facilitate community participation through undertaking joint activities.

Increasing Demand for Support of People with Mild Intellectual Disability

Whilst the inclusion movement gained a foothold in Western society, disability services have faced a growing demand for professional support, also in the Netherlands (Woittiez et al., 2018). In the Netherlands, the population of people with an intellectual disability (IQ < 70) is estimated at 142.000 (Woittiez, Putman, Eggink, & Ras, 2014). Of the 166.000 people that received support from disability services (2011), 72.000 had mild intellectual disability (IQ 50-70), 57.000 had moderate (IQ 35-50) or severe intellectual disability (IQ < 35), and another 37.000 had a borderline level of intellectual functioning (IQ 70-85; Ras, Verbeek-Oudijk, & Eggink, 2013). The profile of the people who apply for disability support has changed. In the past, mainly people with moderate or severe levels of intellectual disability applied for support (IQ 50 or below). More recently, people with mild intellectual disability and a borderline level of intellectual functioning are increasingly applying for professional support (Woittiez et al., 2014).

Social developments may offer a substantial explanation for the growing demand for support for people with mild intellectual disability and a borderline level of functioning (Woittiez et al., 2014). In today's society that is more complex (e.g., more complex jobs, higher demands in education, and digitization), they may experience increased difficulties with functioning adequately without support. Moreover, in modern individualized society, they may experience reduced opportunities to call upon support within close-knit communities (Woittiez et al., 2014). In the Netherlands, people with a borderline level of intellectual functioning who experience difficulties in daily life such

as social interaction, work or self-care are also eligible for support from disability services. In policy and practice, people with mild intellectual disability and a borderline level of intellectual functioning are often considered as a homogenous group. However, research has shown that even though they may experience (partly) overlapping support needs, significant differences may exist between these groups in terms of their vulnerability and the complexity of their support needs (Nouwens, Lucas, Smulders, Embregts, & Van Nieuwenhuizen, 2017). As such, the current thesis focuses on people with mild intellectual disability (IQ < 70) only.

The value of Professionals in Support Networks

Professionals play a major role in the supportive networks of people with mild intellectual disability. This does not only hold true for people living in more segregated residential facilities, but also for those receiving community-based residential support or living independently in the community (Forrester-Jones et al., 2006; Kwekkeboom, De Boer, Van Kampen, & Dorrestein, 2006; Van Asselt-Goverts, Embregts, & Hendriks, 2013, 2015; Verdonschot, De Witte, Reichrath, Buntinx, & Curfs, 2008). Also, professionals are highly valued by people with mild intellectual disability. For example, Kwekkeboom et al. (2006) found that professionals not only provided instrumental support to people with mild intellectual disability living in the community (e.g., help in running their household, managing finances); they were also their rock when experiencing emotional problems, and their friend for going out with. In addition, Van Asselt-Goverts et al. (2013) showed that 25% of the networks of participants with mild intellectual disability, living independently in the community for over two years, consisted of professionals (e.g., support staff). These professionals were highly appreciated by people with mild intellectual disability. They were not only highly valued for their instrumental support; they were also highly rated in terms of affection (e.g., feeling safe and secure with the person) and preference (e.g., preference for contact with the person, liking the contact), with a level that was comparable to family. Some people with mild intellectual disability have even been found to consider professionals to be part of their family (Widmer, Kempf-Constantin, Robert-Tissot, Lanzi, & Galli-Carminati, 2008). It is important to recognize that professionals continue to play a vital role in the lives of people with mild intellectual disability, even in a changing societal context of deinstitutionalization and inclusion. However, until now, studies have not provided an in-depth account of people's experiences with support from staff in the context of their broader lives and social circumstances.

A Sense of Belonging: Enhancing Informal Supportive Networks

Because of increased demands for professional support, there has been a relatively recent emphasis in Western society on supporting individuals to forge stronger links with their local community, with the aim of increasing informal networks of support, while decreasing their need for paid support from professionals (e.g., Malli, Sams, Forrester-Jones, Murphy, & Henwood, 2018; Miettinen, 2012; Woittiez, et al., 2018). This emphasis on informal supportive networks has occurred for two main reasons. The first one is financial; due to growing demands for support from disability services, the costs have increased (Eggink, Pommer, & Woittiez, 2008; Ras et al., 2013) and, as such, the first aim is to reduce costs. Second, by increasing networks of support, the intention is to enhance social inclusion of people with intellectual disability (Cobigo et al., 2012).

Increasing emphasis on informal networks led to major legislative changes in the Netherlands on January 1, 2015. Prior to this, support for adults with intellectual disability was regulated by a general Act that regulated the costs that accompany a disorder or disability [Dutch: Algemene Wet Bijzondere Ziektekosten (AWBZ)]. Since 2015, support is subject to both the Social Support Act [Dutch: Wet Maatschappelijke Ondersteuning (WMO)] and the Long-Term Care Act [Dutch: Wet Langdurige Zorg (Wlz)]. Even though large differences between these Acts exist (e.g., in type of funding or organization), both Acts appeal for increasing use of informal supportive networks. People with intellectual disability who are subject to the Social Support Act can no longer claim professional support by right; professional support is only awarded if the provision of support through informal contacts is inadequate. People who are subject to the Long-Term Care Act maintain their right to professional support, though it is stated that professionals must involve the informal network of the service user and must treat informal caregivers as equal partners in support.

In line with these societal developments, service provider *Dichterbij* aims to provide support that is complementary to support from informal networks and that is created together with informal network members. Currently, *Dichterbij* supports over 2000 people with intellectual disability in the Southeastern part of the Netherlands. Despite the fact that their service users have experienced increased opportunities to live and participate in society, *Dichterbij* recognized that meaningful relationships with other community members and an actual sense of belonging to a supportive informal network is not self-evident for all people with intellectual disability. As such, *Dichterbij* underlined the importance of developing more knowledge on the support experiences of people with mild intellectual disability by facilitating this PhD project.

The Role of Families in Support Networks

Alongside professionals, family members are often the key agents in the lives of people with intellectual disability, and supportive relationships with people in the wider community may be primarily with family (Van Asselt-Goverts et al., 2013; 2015). Families provide a unique set of supports to people and bring important qualities to personal relationships, like unconditional love, a long term view, and emotional closeness; qualities that are often difficult for professionals to replicate (Bigby & Fyffe, 2012).

Over recent decades, research into families of people with intellectual disability has focused mainly on how a child with intellectual disability may affect parental and family well-being (Hastings, 2016). Although families of people with intellectual disability face some significant challenges, concerns, and needs, it is now generally agreed that parental stress and well-being are influenced by many factors, such as child characteristics, family or environmental features, and parents' cognitive styles, and that successful adaption rather than pathology is the norm for many families. Research has also addressed the reverse direction – how characteristics of the family may have an impact on people with intellectual disability. In particular, people with intellectual disability are at increased risk for the development of psychological problems, and factors associated with this increased risk include parental psychological distress and family dysfunction (Dickson, Emerson, & Hatton, 2005; Wallander, Dekker, & Koot, 2006). The bidirectional nature of the relationship between parental/family functioning and psychological outcomes for the family member with a disability has also been considered, indicating that parental and family dysfunction are both an antecedent and consequence of people's behaviour problems, and vice versa (Greenberg, Mailick Seltzer, Hong, & Orsmond, 2006; Orsmond, Mailick Seltzer, Krauss, & Hong, 2003).

Families are often the main provider of informal support to people with intellectual disability (Sanderson, Burke, Urbano, Arnold, & Hodapp, 2017), and may be the primary source for expanding their social network to members in the local community, apart from the service provider (Overmars-Marx et al., 2014). Despite the recognition that the family is an important influence on the development, well-being and social inclusion of children and adults with intellectual disability, very little research has considered the perspective of people with intellectual disability about their families. Existing research has included a small number of qualitative studies about their family support experiences (e.g., Kramer, Hall, & Heller, 2013; Walmsley, 1996; Williams & Robinson, 2001). For example, Kramer et al. (2013) showed that reciprocity in relationships with siblings seemed to consist of siblings with disabilities enacting their family roles, such as fulfilling a role as an aunt or uncle and their siblings providing them with access to resources in the community in return. The research literature requires a theoretical

foundation and associated method to build knowledge on how people with intellectual disability conceive of their family and how they perceive the supportive resources within their families. The Kramer et al. (2013) study showed that social capital may be a useful theoretical framework in understanding support in relationships with family.

The Theory of Social Capital

The concept of social capital has attracted increasing attention from interdisciplinary research and policy makers. Very broadly defined, social capital is about human relationships and networks, in contrast to cultural capital (i.e., skills and knowledge of individuals), and economic capital (i.e., finances)(Bourdieu, 1986). However, there is much debate on what constitutes social capital and how it should be measured (Tzanakis, 2013). Even though the idea behind social capital is not new (the value of human relationships has already been described by sociologists like Émile Durkheim and Karl Marx)(Portes, 1998), Pierre Bourdieu (1986), James Coleman (1988), and Robert Putnam (1995) proposed the three dominant approaches to social capital. It is beyond the scope of this thesis to explain these approaches in detail, though a brief overview of the different approaches is presented. According to Bourdieu (1986), social capital is about the resources that flow to individuals from their membership of durable social networks of mutual recognition. Bourdieu emphasizes that social capital (i.e., resources) is inequitably distributed by social class, and the role of inequitable power relations in determining the resources available to individuals through their social networks is central to his theorizing. Unlike Bourdieu, Coleman and Putnam do not explicitly recognize the role of power and inequality. For Coleman, the social capital that is integral to social networks is about the structural characteristics of the network (e.g., how members of the network are connected to each other). Access to valuable resources that are present within the structure of the social network will contribute to achieving personal gain. While Bourdieu and Coleman mainly focus on the role of social capital in achieving personal gain, Putnam emphasizes the ability of social capital to connect communities and conceptualized social capital as a community-level resource and public good. For Putnam (1995) social capital refers to: "Features of social organizations, such as networks, norms and trust that facilitate action and cooperation for mutual benefit" (p. 67). Despite the different definitions of social capital, there seems to be consensus that "social capital stands for the ability of actors to secure benefits by virtue of membership in social networks or other social structures" (Portes, 1998, p. 6).

Family Support as Social Capital: Bonding and Bridging Social Capital and the Norm of Reciprocity

As families involve a social structure of connections among individuals in which support is often provided, families are considered a significant source of social capital (Furstenberg & Kaplan, 2004; Widmer, 2016). From a social capital theoretical perspective, positive and supportive family relationships (i.e., family-based social capital) are proposed to have a variety of positive outcomes for individuals, such as enhancing their physical and mental health (Kawachi & Berkman, 2001; Kawachi, Kennedy, & Glass, 1999; McPherson et al., 2014; Riumallo-Herl, Kawachi, & Avendano, 2014). Support within relationships is often differentiated into emotional and instrumental support. Emotional support is believed to be the most significant type of support and found to be a stronger predictor for positive physical and mental health than instrumental support (Berkman, 1995; Thoits, 1995; Viswesvaran, Sanchez, & Fisher, 1999). Moreover, it has been found that people attribute an emotional meaning to supportive behaviours that are instrumental in nature. That is, by providing instrumental support someone may show that they are caring and have an understanding of another person's needs (Semmer et al., 2008).

Two main kinds of social capital are described in the literature and are of relevance in relation to the family: bonding and bridging social capital (Coleman, 1988; Burt, 1995). First, bonding social capital refers to network closure (i.e., a high density of connections among network members) (Coleman, 1988). In dense networks, all or most individuals are interconnected, resulting in enhanced expectations, obligations, and trust among them. In dense networks, support often has a collective nature. For example, when one member of a dense network fails to provide support, it is likely that the other members will jointly react against this person. Second, bridging social capital refers to the position in which individuals (named "brokers") are able to mediate the flow of resources among network members, due to the absence of relationships in a network that create relational holes in its structure (Burt, 1995). Therefore, "brokers" are able to influence others. As such, fulfilling a "broker" function may lead to feelings of autonomy, control, and competence (Burt, 1995). As families were believed to be constituted primarily by the nuclear family (i.e., married couples and their children), they have traditionally been regarded as a source of bonding social capital. However, in late-modernity family contexts have become more open and heterogeneous (Allan, 2008; Widmer, 2016), and more recently it has been shown that family contexts based on blood ties provide a bonding type of social capital, whereas family contexts based on friendships and more extended family (e.g., in-laws, and step-family) usually provide bridging social capital (Aeby, Widmer, & De Carlo, 2014; Widmer, 2006, 2007).

Another important theoretical concept related to the theory of social capital is the norm of reciprocity (Gouldner, 1960). Social capital is about the reciprocal exchange of supports or resources between people (Bullen & Onyx, 1999). Exchange within close relationships such as family does often not hold an "immediate return" requirement, but is based on the expectation that someone will return the favour sooner or later, and reciprocity will be accomplished eventually (Antonucci & Jackson, 1990; Torche & Valenzuela, 2011). However, for certain groups of people, such as children, the elderly, or people with disabilities, reciprocity might fail and the norm of beneficence appears, meaning that people support others regardless of the other's future ability to return the favour (Gouldner, 1960, 1973). Being able to provide support to other people may enhance feelings of self-worth and self-esteem (Forrester-Jones & Barnes, 2008; Liang, Krause, & Bennett, 2001), and an over-benefited position with more received than given support may have less favorable outcomes for the individual in terms of well-being and mental health than a more balanced or even an under-benefited position (Fyrand, 2010; Thomas, 2010). These findings are in line with Cobigo's al. (2012) definition of social inclusion in which it is stated that for people with intellectual disability to experience social inclusion it is important to belong to a social network within one not only receives, but is also contributes support.

Social Network Measurements

To date, several instruments have been used to examine social network characteristics of people with intellectual disability, such as the Social Network Guide (SNG; Forrester-Jones et al., 2006), the Social Network Map (Robertson et al., 2001; Tracy & Abell, 1994), the Social Network Questionnaire (Dagnan & Ruddick, 1997; Krauss & Erickson, 1988), the Social Support Self Report (SSSR; Lippold & Burns, 2009; Lunsky & Benson, 1997), and the Hierarchical Mapping Technique (i.e., Circles Task) (Antonucci, 1986; Lippold & Burns, 2009). These instruments provide researchers with detailed information on the structural and functional social network characteristics of people with intellectual disability, including their own views. The existing instruments were developed to assess the supportive relationships that existed between the person with intellectual disability and his/her network members, and most of them focused on support received by the person with intellectual disability (Antonucci, 1986; Dagnan & Ruddick, 1997). Even though some instruments (i.e., Social Network Map, SSSR, and the SNG) also examine how the person with intellectual disability contributes support, thereby assessing the reciprocal character of the person's supportive relationships (Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001), none of these instruments examine the broader network structure of interdependencies among network members in which,

for example, intimate relationships, close friendships, or parent-child relationships are embedded. In addition, none of the existing instruments has a specific focus on the family – although all would potentially capture elements of support from family members.

An instrument that has been developed to explore family relationships from a social capital theoretical perspective is the Family Network Method (FNM; Widmer, Aeby, & Sapin, 2013). Widmer (2016) has argued that family research has traditionally focused on a small number of family dyads (i.e., marital couples, parents and biological children, or siblings), in which it is predefined what constitutes the family. However, to capture the heterogeneity of contemporary family contexts, family researchers need to go beyond dyadic research and examine more broadly how people define their family context and how the relationships within this family context are intertwined (Widmer, 2016). For that reason, the FNM explores how individuals define their family contexts, and more specifically how they perceive existing supportive relationships in these contexts. Dyadic relationships (between a person and his/her network members) cannot be seen as isolated from the broader social context. To examine the family-based social capital of the FNM respondents, they are not only asked about their own relationships with family members (i.e., the ones who they consider to be their family), but also about their views of relationships amongst the different family members who make up their network. Even though the FNM was developed for use in the general population, it has previously been used to examine the family-based social capital of people with mild intellectual disability in studies of an exploratory nature (Widmer et al., 2008; Widmer, Kempf, Sapin, & Galli-Carminati, 2013). However, due to cognitive and language impairments, instruments developed for the general population cannot be automatically applied to people with intellectual disability; they might experience difficulties in understanding questions and communicating valid and reliable answers (Coons & Watson, 2013; Finlay & Lyons, 2001). It is important to systematically pilot and adapt instruments, and to report the procedures that were used to facilitate the understanding of people with intellectual disability, to enhance the transparency and transferability for use in the population of people with mild intellectual disability, and to reliably examine their family support experiences.

Aims and Outline of the Thesis

In sum, to experience social inclusion, one of the key features is to have access to social capital (i.e., to belong to a social network within one receives and contributes support). Alongside professional support, family members are often the main provider of informal support and may fulfill a key role in the social inclusion of individuals with mild

intellectual disability. However, studies on the provision of family support have rarely included the experiences of individuals with mild intellectual disability themselves, and, in addition, the research literature requires a theoretical foundation. Gaining insight into the experiences of family support from people themselves is of great importance, as they are the experts and authorities on their lives, experiences, and feelings (McDonald, Kidney, & Patka, 2013; Lunsky & Benson, 1997). Therefore, the first aim of this thesis was to contribute to family support theory and broaden the understanding of the family support experiences of people with mild intellectual disability, within a social capital theoretical perspective. More specifically, this thesis focuses on family support of adults with mild intellectual disability who live apart from family with support from a service provider, and centres on the support experiences of people with mild intellectual disability themselves. In addition, since perceived emotional support is regarded as the most significant type of support (Berkman, 1995; Thoits, 1995; Viswesvaran et al., 1999), the focus of this thesis is on emotional support.

In addition, it has been shown that professionals continue to play a vital role in the supportive networks of people with mild intellectual disability, even when they are physically included in the community. However, until now, studies have not provided an in-depth account of people's experiences with professional support in the context of their broader lives and social circumstances. Therefore, the second aim of this thesis was to establish an in-depth account of the experiences of people with mild intellectual disability with respect to living with support. A broader understanding of the lives of people with mild intellectual disability who are supported professionally is important, first, to better understand why professionals continue to play such a significant role for people and, second, to interpret the family support experiences of people with mild intellectual disability within the broader context of living with professional support.

The current thesis consist of seven chapters, of which this general introduction is the first. The study in **Chapter 2** explored in detail what six individuals with mild intellectual disability thought and felt with regard to living with professional support, and thereby reports an in-depth account of their experiences, using Interpretative Phenomenological Analysis (IPA) as the qualitative method. **Chapter 3** reports on the systematic piloting of questioning people with mild intellectual disability about their family support experiences using the Family Network Method. This chapter describes in detail why adaptations were needed and how adaptations were made to the original FNM, resulting in the Family Network Method – Intellectual Disability (FNM-ID). Furthermore, it sets out how the FNM-ID provides rich, theoretically significant information on emotional support in the family networks of individuals with mild intellectual disability. The FNM-ID addresses experiences of both receiving and contributing support, and thereby assesses the reciprocal nature of the person's support experience and, in addition, maps

the broader network structure of interdependencies among all members of the network in which support relationships with network members are embedded. Data obtained by the FNM-ID can be analysed quantitatively using social network analysis to yield key measures of interest within a social capital framework. **Chapter 4** contains a descriptive study on the family support experiences of 138 people with mild intellectual disability (aged 18-40 years). It systematically describes the way in which they defined their family group as well as the supportive relationships within this group, thereby assessing the social capital their families provided (using the FNM-ID). In addition, this study provides a detailed description of the reciprocal nature of the emotional support in relationships with family members, as perceived by people with mild intellectual disability. **Chapter 5** describes the examination of the family support networks of people with mild intellectual disability (aged 18-40 years), by assessing both their own perceptions (n = 111) and the perceptions of their family members (n = 111), and comparing both perspectives on the key social network measures of interest within a social capital theoretical framework. In addition, this study examined what factors were associated with any diverging perceptions. The study in **Chapter 6** examined the views of 53 emerging adults (18-25 years) with mild intellectual disability about their family support networks and compared these views to those of 53 students without intellectual disability of the same sex and age (using the FNM-ID). As such, this study provides insight into how the characteristics of the (significant) family networks and the support experiences of people with a mild intellectual disability compare to the network characteristics and family support experiences of emerging adults without intellectual disability. Family networks of the emerging adults with mild intellectual disability were compared to those of students without intellectual disability on the key social network measures. This study demonstrates how the family-based social capital of young adults with mild intellectual disability is different from that of students without intellectual disability. Finally, in the general discussion of **Chapter 7**, the findings, strengths, and limitations of the current thesis are summarized. Also, implications for future research, policy, and practice are discussed.

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CHAPTER 2

2

Living with support: Experiences of people with mild intellectual disability

This chapter has been published as:
Giesbers, S. A. H., Hendriks, A. H. C., Jahoda, A., Hastings, R. P., & Embregts, P. J. C. M. (2019). Living with support: Experiences of people with mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 32*(2), 446-456. http://dx.doi.org/10.1111/jar.12542

Abstract

Background

To enhance social inclusion of people with intellectual disability, policy is aimed at increasing informal support networks. Nevertheless, staff continue to play a vital role in their support networks.

Method

Six individuals with mild intellectual disability, living in community-based-settings, were interviewed following a semi-structured format. In-depth accounts of participants' support experiences were established using Interpretative Phenomenological Analysis.

Results

Three main themes were identified: Relationships with staff placed within a personal history, relationships with staff within an organisational context, and staff support and interviewees' place in the world.

Conclusions

Relationships with staff were often one of the closest and most significant social relationships participants have. As living in the community had not necessarily led to meaningful inclusion for participants, the findings point at the important role of staff in supporting and facilitating friendships and close relationships of people with intellectual disability.

There has been increasing recognition that people with intellectual disability are full citizens with the same rights as non-disabled persons and that they should be supported in making their own decisions and participating equally in society (Devi, 2014). Participation and social inclusion have dominated the policy discourse within western society (e.g., Hewitt, Nord, Bogenschutz, & Reinke, 2013). For example, in the Netherlands, rights for people with disabilities have been officially acknowledged by the relatively recent (2016) ratification of the United Nations' Convention on the Rights of Persons with Disabilities (UNCRDP; United Nations, 2006). The perspective of people with intellectual disability themselves has become a central aspect in support provision. They should determine, as far as possible, their own support needs and should have a say in how this support is provided (Embregts, 2011).

To enhance participation and social inclusion, there has been an emphasis on supporting individuals to forge stronger links with their local community, with the aim of increasing informal networks of support and reducing the need for support from paid carers. However, research has shown that the social networks of the majority of people with intellectual disability are relatively small (Lippold & Burns, 2009; Van Asselt-Goverts, Embregts, & Hendriks, 2013). Interactions between people with intellectual disability and those in the wider community may be mainly restricted to family and staff, not only for people with intellectual disability living in residential campus-style settings but also for those living independently or receiving community-based residential support (Forrester-Jones et al., 2006; Kwekkeboom, De Boer, Van Kampen, & Dorrestein, 2006; Robertson et. al. 2001; Van Asselt-Goverts, Embregts, & Hendriks, 2015; Verdonschot, De Witte, Reichrath, Buntinx, & Curfs, 2008). For example, Van Asselt-Goverts et al. (2013) found that around a quarter of the social networks of participants with mild intellectual disability consisted of professionals (e.g., support staff). These professionals were highly valued by people with mild intellectual disability, who relied on them for emotional and instrumental support. Thus, professionals continue to play a vital role in the lives of people with intellectual disability. Therefore, it is important to gain insight into how they perceive the support they receive from professionals or staff (McDonald, Kidney, & Patka, 2013).

Several researchers have examined how people with intellectual disability and additional psychological problems perceive the support they receive from specialist mental health services, forensic services for people with intellectual disability and mainstream mental health services (Clarkson, Murphy, Coldwell, & Dawson, 2009; Donner, Mutter, & Scior, 2010; Longo & Scior, 2004; Griffith, Hutchinson, & Hastings, 2013; Murphy, Estien, & Clare, 1996; Stenfert Kroese, Rose, Heer, & O'Brien, 2013). Relationships with staff that are based on qualities such as trust, honesty, patience, a genuine interest and a caring attitude were highly appreciated. However, some

individuals found staff to be unfriendly or arrogant, unavailable, immature, short tempered, and reluctant to help. Others appeared acutely aware that not all staff had an interest in working with them.

Little research has addressed the perceptions of people with intellectual disability without additional psychological problems who receive support within intellectual disability services. In a study by Kwekkeboom et al. (2006), 17 individuals with mild intellectual disability talked primarily about the emotional support they received from staff. Additionally, Reuzel, Embregts, Bosman, Van Nieuwenhuijzen, and Jahoda (2017) explored the perceptions and expectations of regular support meetings of people with mild to borderline intellectual disability. Interviews with nine participants immediately after their support meeting showed that during the meeting they received helpful advice from staff. They also appreciated practical support and the opportunity to tell their story. The outcomes that they listed were consistent with the goals and expectations they outlined before their meetings.

Finally, other researchers have focused on what people with intellectual disability regard as important qualities of staff. They have stressed the importance of staff's interpersonal skills. They also valued relationships with staff characterized by attentiveness, care, availability, reliability, trust, and honesty (Barelds, Van Goor, Van Heck, & Schols, 2010; Roeden, Maaskant, & Curfs, 2011; Roeleveld, Embregts, Hendriks, & Van den Bogaard, 2011). People with intellectual disability placed more of an emphasis on interpersonal skills when defining the qualities they value in staff than staff themselves or service managers, who placed the greatest emphasis on practical skills, knowledge, and managing staff stress (Dodevska & Vassos, 2013; Hatton, Wigham, & Craig, 2009). Furthermore, Roeden et al. (2011) found that people with intellectual disability want to feel that their independence and autonomy are respected by staff. As far as possible, they wanted to solve their own problems. Petner-Arrey and Copeland (2014) found that people with intellectual disability considered a caring relationship to be one that promoted their autonomy. However, staff were not always attuned to their needs and wishes, often helping them with tasks they were capable of doing themselves.

Until now, studies have not provided an in-depth account of people's support experience in the context of their broader lives and social circumstances. Therefore, in the present study, we used Interpretative Phenomenological Analysis (IPA) as the qualitative method to explore what individuals with intellectual disability thought and felt with regard to their support from staff (Smith, Flowers, & Larkin, 2009). IPA is a suitable approach when one is trying to explore how individuals perceive situations they are facing (i.e., receiving support from staff within services), and how they make sense of their personal and social world. The goal of IPA is to address how individuals make sense of events or aspects of their lives which, in turn, are embedded in their

broader personal histories and social contexts. Published IPA studies typically have included samples of five to ten participants (Smith, 2004). Small sample sizes allow for in-depth engagement with each individual case, and a detailed exploration of similarities and differences between participants (Smith et al., 2009). By using IPA, we aimed to develop a better understanding of the unique experiences, challenges, and needs of adults with mild intellectual disability with regard to their support.

Method

Participants

A purposive sample of six individuals with mild intellectual disability took part in the study: four men and two women. Characteristics of participants are provided in Table 1, and pseudonyms are used throughout to protect anonymity. The mean age of participants was 27.7 years. All participants received support within a clustered care setting and had set times for one-to-one support, but they were able to ask for additional support 24 hours a day. Staff were either based in the same or an adjacent building. All participants received support under the Dutch Long-term Care Act (Wlz). Under this act, one of six care profiles is assigned to the individual, based on the person's level and type of support needs.

Semi-Structured Interview

In line with the IPA method, we used semi-structured interviews. An interview schedule with key topic areas was developed for use in the study. The interviews covered: (a) the nature of support received by the participant (i.e., when, where, and by whom is the person supported), (b) the participant's experience of support and perceived support needs (i.e., views about what support is needed and what support is provided), (c) evaluation of support (i.e., how does the person view the kind of support he/she is given and how is the support delivered), (d) the nature of the person's relationship with the support person and the nature of support he/she receives (i.e., how do the person and staff get along), and (e) the meaning of living with support (i.e., how does the person experience being supported by professionals). The schedule was piloted and discussed with two experts-by-experience of having intellectual disability and receiving supports from services. Subsequently, minor changes were made before carrying out the interviews reported in this study.

Procedure

After ethical approval was obtained from the Ethical Review Board of Tilburg University (EC-2015.33), as well as from the review boards of the participating services, participants

Table 1. Characteristics of Participants

	Participants (Pseudonyms)					
Variable	**Lynn**	**Kenneth**	**Daniel**	**Jill**	**Thomas**	**Brian**
Gender	Female	Male	Male	Female	Male	Male
Age (years)	23	27	32	30	22	32
Living situation	Together with another person with ID	Individually	Individually	Individually	Individually	Together with another person with ID
Additional diagnose	None	None	Motor impairment	None	Epilepsy, ADHD	Motor impairment, Epilepsy
IQ score	61	58	54	60	58	60
Daytime occupation	4 days a week	3 days a week	5 days a week	2 days a week	5 days a week	5 days a week
Level of support	2: living with support and more intensive input	1: living with support	1: living with support	4: living with more intensive help and behavioural support	1: living with support	1: living with support
Number of support hours	12.5 – 15.0	10.5 – 13.0	10.5 – 13.0	15.0 – 18.5	10.5 – 13.0	10.5 – 13.0

were recruited from two services supporting people with intellectual disability in the Netherlands. Criteria for inclusion of participants were that they: (i) had mild intellectual disability (IQ scores between 50 and 70) (ii) were aged between 18 and 40 years, and (iii) had received community-based support from the service provider for at least six months. Participants were invited in consultation with key staff members of the service providers. An information letter (covering the content of the study, the financial recognition for participation [10 euro cash], and the confidentiality of the data) was sent to participants. Interviews took place at the homes of participants.

To ensure that participants could provide informed consent, a standard procedure was followed as described by Arscott, Dagnan, and Stenfert Kroese (1998). At the start of each interview, a verbal and written overview of the research project was presented by the interviewer. The interviewer determined whether participants could recall: (i) an idea of the content of the proposed interview; (ii) that they would be interviewed once, (iii) possible positive and adverse aspects regarding participation, and (iv) that they would be free to withdraw at any time. If the participant did not initially understand the research, the researcher repeated and explained these four points in simpler or alternative words until the participant was able to respond to the consent questions, indicating that they understood the key aspects of the research procedure. Following these adjustments, all participants were able to provide informed consent.

Interviews were conducted by the first author in an open and flexible manner with topics being covered according to the direction taken by the participants, aiming to initiate a dialogue with participants, while remaining open to other subjects raised by the participants themselves. At the end of the interview, participants were given the opportunity to raise additional topics. The duration of the interviews ranged from 18 minutes to 1 hour and 24 minutes with a mean duration of 53 minutes. Interviews were audiotaped with the participants' informed consent and then transcribed verbatim.

Analysis

Data were analysed using IPA. IPA is concerned with the detailed exploration of how people make sense of their personal and social world (Smith & Osborn, 2008). The aim is to explore an individual's personal perception or account of an event or experience as opposed to an objective description of the object or event itself. IPA is a dynamic process based on the assumption that the researcher has an active role in the research process; the researcher influences the extent to which they access the participant's experience and how they interpret and make sense of that experience.

Data analysis was carried out by the first author and followed the stages set out by Smith et al. (2009). The first stage involved the close reading and rereading of the transcript to become familiar with the interview content. Second, the transcript was read through line by line, noting points of interest and significance on a descriptive, linguistic and conceptual level. Third, the transcript and initial notes were re-read, with emergent themes noted. At the fourth stage, themes that were considered as connected were grouped into overarching themes and given a descriptive label, after which these groups of themes were discussed within the research team. As a result, some additional changes were made in the grouping or descriptive labelling of themes. To ensure that the analysis was carried out in a rigorous way and that interpretations made by the first author were of an explicit nature, all stages involved a discussion with a second researcher to provide an audit of the analysis. Also, a reflective journal was kept to map all the decisions that were made. These stages were repeated for each transcript after which the overarching themes for each interview were compared and discussed with the research team to find patterns across cases. As the interviews were carried out in Dutch, the initial analysis was conducted in the same language. Findings were then translated into English for discussion with the international research team. To ensure the meaning of what people talked about was kept during the translation process, the findings and the final paper were discussed with an English native speaker who was fluent in Dutch.

Results

The three overarching themes that emerged were: (A) relationships with staff placed within a personal history, (B) relationships with staff within an organisational context, and (C) staff support and interviewees' place in the world.

Theme A: Relationships with Staff Placed within a Personal History

Across interviews it became clear that the nature and meaning of relationships with staff needed to be understood in the context of participants' social histories. All participants placed a high value on staff being people who were there for them, although this held various meanings for them. Four participants thought that staff 'being there for you' meant that they were one of the closest and most significant social relationships they had. The salience of these relationships with staff was juxtaposed with the difficulties the participants had forming close and confiding relationships with people in the wider community. For example, Kenneth, a 27 year old man who lived in his own apartment in the community, described the lack of significant relationships in his life, such as family relationships, friendships, or an intimate relationship, and talked about his frustrations about this.

"So I became friends with myself, just trying to keep myself as a friend. You are born alone and eventually you will die alone as well. That is just how it is. And in the meantime, you have to be lucky to meet someone. I have not been lucky in that way. I have not been that lucky when it comes to love, because I have never had a girlfriend. And that is frustrating, you know. Really, it is the most frustrating thing." (Kenneth)

Kenneth experienced feelings of loneliness and social exclusion and felt that it was vital to have someone there for him, unconditionally. As a result, he wanted to develop close, informal relationships with staff. However, because staff failed to live up to his expectations, he often became frustrated with them, complaining that they had limited time, did not always pay proper attention to him, and could be distant and formal in their approach. Kenneth found it particularly hard to cope with the idea of having a distant relationship with young, female staff whom he found attractive.

"There are some pretty nice staff members around here, which has always been a pitfall. You see, there are a lot of female staff working at (name of service provider). Some of them are really young and occasionally I have even had a crush on one of the staff members. Then they will say: 'You should not get a crush on staff members'. Yeah, okay, they are talking nonsense. Getting a crush on them can happen, right? That is just normal." (Kenneth)

Consequently, Kenneth disliked being supported by younger female staff, because he felt uncomfortable talking to them about his feelings of loneliness, his need for intimacy and about his problems in general. Instead, he preferred relationships with staff who were older than him and who he could regard as 'mother' figures. Kenneth also thought that older and more experienced staff members were wiser and able to give better advice about sensitive topics than younger staff.

Lynn, Daniel and Brian also valued their social contact with staff and informal interactions that were not directly support-related, such as having a chat, drinking coffee, playing videogames, and going out together (e.g., going for a drink/dinner or sports game). They particularly enjoyed one-to-one social activities with staff.

"It was also nice that I could do something with just my key support worker, doing something together, solely with her. Having dinner and a talk, that is what we did. (…). We went for dinner and a soccer game. Yeah, it's really nice going to do things and then you have more time for each other and you can also have a chat, because you have more time for one another." (Daniel)

Contrary to Kenneth, Brian, Daniel, and Lynn's experiences, Thomas and Jill talked about meaningful contact or 'being there for you' in a way that was mainly related to practical support. They appreciated being able to talk about their problems and getting information and advice that they needed from staff. For example, Thomas, a 22 year old man who lived in his own apartment, talked about how staff are always there for him when he does not understand certain information or if he does not know how to deal with something.

"They give me good advice and tips, such as 'hey, this is the best way to do that'. Instead of what I had in mind. And if I have planned something and I want to do it, then I have the feeling that it usually goes wrong." (Thomas)

Interestingly, Thomas highlighted the significance of his family and particularly his mother, when being interviewed about his staff support. He talked about the way staff and his mother discussed important matters. Moreover, he said that he talked to his mother when he was having problems with staff, and explained how his mother stood up for him. Thus, he appeared to make sense of his relationship with staff in the context of his relationship with his mother, who lived close-by and had been actively involved in supporting him throughout his life. Furthermore, Thomas talked about the significance of his friends, feeling they are there for him when needed.

"It was quite difficult for me to speak about, and my friends understood that and helped me a lot: either they texted or called me. Asked me how I was doing. Yeah, then I think to myself, those are real friends, they just ask you how you are doing. Yeah and that sort of thing. That makes me feel good." (Thomas)

Like Thomas, Jill (a 30 year old woman with a history of frequently moving of home) talked about her relationship with staff in a way that was mainly support related (i.e., talking about problems, and help with finances). However, her experience with staff was quite different from Thomas'. It seems she had developed a general lack of trust towards staff due to negative past experiences.

"In other organizations that was an issue. They treat you like you are some kind of criminal or… that you are less than them, you know what I mean? And....especially that. That you are less than them. And I'm not, nobody is. Everyone is the same. So why would you treat someone like that?" (Jill)

As a result of negative past experiences, Jill tended to withdraw from staff and even, on some occasions, to refuse support, despite experiencing a different approach of staff in which she felt to be treated like an equal.

"I've never experienced that before. That they treat you as an equal. It creates trust. It creates trust in the people who work here. For me that is very important." (Jill)

Although Jill talked about having developed more trusting relationships with her current staff, she preferred to have minimal contact with them.

Theme B: Relationships with Staff within an Organisational Context

Continuity of support was very important to participants. Brian talked about receiving support from two main staff members, from one of them for more than 9 years, since he had moved in with his current service provider. He felt this continuity had allowed him to build a close personal relationship with his support worker and that she had developed great insight into his support needs.

"She has been my key support worker right from the start. So, yeah, that is quite a difference. And through that you build something together. You don't have to agree on everything, but you build something together. (…) You get to know each other, you get to know each other better. She comes to understand me better. That I am emotional at the moment, or glad or happy. She can tell from my face when something is going on." (Brian)

Consequently, Brian said he would only talk to this key worker when he had a problem or felt emotional. However, he reported that the other staff member found it difficult to accept the bond he had developed with his main support worker and tried to force him to talk about personal matters with her as well.

"Yeah and my key support worker knows that. She knows me much better. She already had the first piece of paper in her hands, she has been involved from the beginning up till now. So she knows what I am like. And the other [staff member] still tries to see how far she can go." (Brian)

In contrast to Brian, Daniel talked about being supported by a large team of staff with a high turnover. As a result, Daniel seemed to have few personal relationships with staff and often felt rejected by them. Moreover, he thought that staff tended to favour other people with intellectual disability.

"And then every time that other clients call she says: 'Yeah I'm with Daniel at the moment, but I will be with you as soon as possible'. Then she asks me if I have anything else that I would like to say. Yes, of course I have, but then she says: 'Okay, but I do not have much time, I really have to move on to the next client'. So she is with me for an hour or so, maybe a bit longer. So, then I think: If you have to go, just go." (Daniel)

However, like Brian, Daniel did value the relationship he had with his key worker and the support she provided. He felt she was there for him in a genuine way.

Like Daniel, Kenneth also talked about high staff turnover due to cuts in services. This meant that Kenneth had no say over which staff members would stay or go. His support hours were also cut back, adding to his sense of abandonment. The loss of staff members, with whom he had developed a close bond, was particularly keenly felt.

"Unfortunately we are not the ones who get to decide who [which staff members] we would like to keep, that is up to the Board of Directors. And the Board does not always go along with our choice. That sucks. You see, those people in charge of the organisation have no idea what is going on in the workplace." (Kenneth)

Lynn and Thomas talked about how upsetting it was to be supported by a staff member who was unsympathetic.

"So, because I hadn't taken my medication I had such a stomach ache. I had to have my medication, otherwise I didn't think I could make it through. Then my roommate pushed

the button [call for assistance]. Then she [staff member] came and asked me what I needed. I asked her if I could have my medication and she said: 'Can't you just wait?'… drama, drama, drama… and then eventually she gave me my medication." (Lynn)

As Thomas and Lynn both had low levels of self-esteem, these negative interactions with staff were especially troublesome and, as a result, they were particularly affected when staff were judgemental. It seemed that Thomas and Lynn were in quite a vulnerable position, as they were not really able to stand up for themselves when ill-treated by staff. Instead, they seemed dependent on other staff or relatives to call those staff members to account.

Jill's past negative experiences with staff need to be understood in the context of frequent moves to different residential settings, resulting in frequent changes in staff. Jill felt she had never fitted in to the health and social care system, and had even been homeless for a period, living on the streets.

"This has been my first permanent residence in, well, one and a half years. (…) I lived on the streets, and, well, in other institutions and such like, here and there all over the country actually. Yeah, there was never a permanent place for me." (Jill)

Jill felt disappointed with the system and with staff in general. Consequently, she wanted to be able to choose the type of support she needed and appreciated the fact that her current staff team were respecting her wishes.

Theme C: Staff Support and Interviewees' Place in the World

A third theme that emerged from the interviews concerned how the participants viewed their disability and need for support, and the impact this had on their sense of self and wider lives. Participants talked about their experiences of stigma related to the fact that they receive support. For example, Brian talked about his experience of prejudice and rejection when people found out that he lived in housing with the support of a service provider.

"Then they ask me where I live. (…) I live in a house with a roof, supervised independent living. In housing of service provider (name service provider). (…) Then you can hear, you can already see, you can already feel that they are going to deal with you harshly. That they won't look at you anymore, or with a cross face, or … um, yeah, always something. Well, there is always something bad coming." (Brian)

Kenneth was acutely aware of the negative societal attitudes towards those receiving specialist support.

"We are normal people too. But people outside [in the broader society], they don't see that that easily. They just think: oh, they are THAT kind of person." (Kenneth)

Kenneth also felt that his family held prejudicial views. He thought his family regarded all people with intellectual disability, including himself, as having a severe disability and rejected him because of these perceptions.

"They [family] have never visited me, they've never cared for me. And if I meet them, they act strangely towards me. Because I live within housing with support of a service provider. They have a weird perception of that. They see the website [of the service provider] and they see that kind of people [people with more severe disabilities]. Then, straight away, they have an image in their head and I think: Yeah, hang on, that is not how it works. A variety of people with various backgrounds live in accommodation provided by (name of service provider)." (Kenneth)

In addition, Kenneth felt that living in specialist housing for more than 20 years has been a barrier to forming friendships and close relationships with people in the wider community. This is something he feels powerless to change, adding to his feelings of loneliness and exclusion from society.

"Listen, do you know what the problem is with our society? People who have nothing to do with support services. I live here in care and that is something that works for me. When you live in care, in an organization for people with disabilities, then it is harder to become part of a group. Because those people [in the broader society] have their own lives, they grew up together, and then I come along. That is not appreciated. Because they already have a good thing going with their friends and you are not needed. And that sounds harsh." (Kenneth)

Participants talked about their struggles with accepting their disability and, as a consequence, their support needs. For example, Brian expressed contradictory views about his support needs. On the one hand, he said that he accepted his need for support in some areas of his life and that it can be helpful. On the other hand, he talked about the fact that it can sometimes be difficult for him to accept that he cannot manage on his own.

"When there really is no other way, I will ask for help. Whether you are able to accept that, that is another thing. But I cannot do the impossible, so then I will ask for help." (Brian)

The way Brian talked about his struggle with receiving and accepting support suggests an ambivalence towards his support needs. Brian spoke with an irritated tone of voice about how he sometimes feels patronized by staff. In these situations he felt that staff treated him like a child. At other times, he talked about feeling comforted by the reassuring gestures given by staff and acknowledged that he needed and valued the support he received. Brian's ambivalence towards his support needs perhaps suggests an underlying struggle with his identity and the sensitivity with which his support is provided.

"A pat on the head. On one hand I can understand it, they do mean well. And secretly, I do know that it will put me at ease. In one way that is nice but on the other hand I think to myself: I'm not a child of five, seven years old who needs a pat on the head." (Brian)

It was important to Brian that staff let him try to perform tasks as independently as possible. He felt irritated towards staff who did not allow him the chance to be as independent as possible. He thought that some staff were too quick to take over tasks from him and that they should not underestimate the abilities of people with intellectual disability.

Furthermore, the struggle with identity and the acceptance of their disability seemed, to some extent, related to how they felt judged by other people. When Brian talked about being rejected when people found out he lived with support, he said that those experiences made him worry about his disability and related support needs, leading to a sense of difference and not being "one of them".

"Because I have a care package where I can rely on care 24 hours a day, even during the night when needed, I sometimes think: Why am I the one who has this? Why do I have this? Why did this happen to me? Then I start to question myself. That is going to keep nagging at me. I know the answer, but I can't leave it alone." (Brian)

Kenneth's experience was similar to Brian's, though somewhat different as he said that he had experienced difficulties in accepting his disability in the past, but had now come to terms with it. As stated previously, Kenneth often felt that other people regarded him as different and he also felt excluded and rejected. However, it was noticeable during the interview that Kenneth frequently and firmly stated that he felt just as good as anybody else and focused on the things that he is able to do. Moreover, he asserted that his abilities are equally as important as those of anyone else in society. This appeared to be a way of defending his self-worth in a society where he did not feel accepted for who he is.

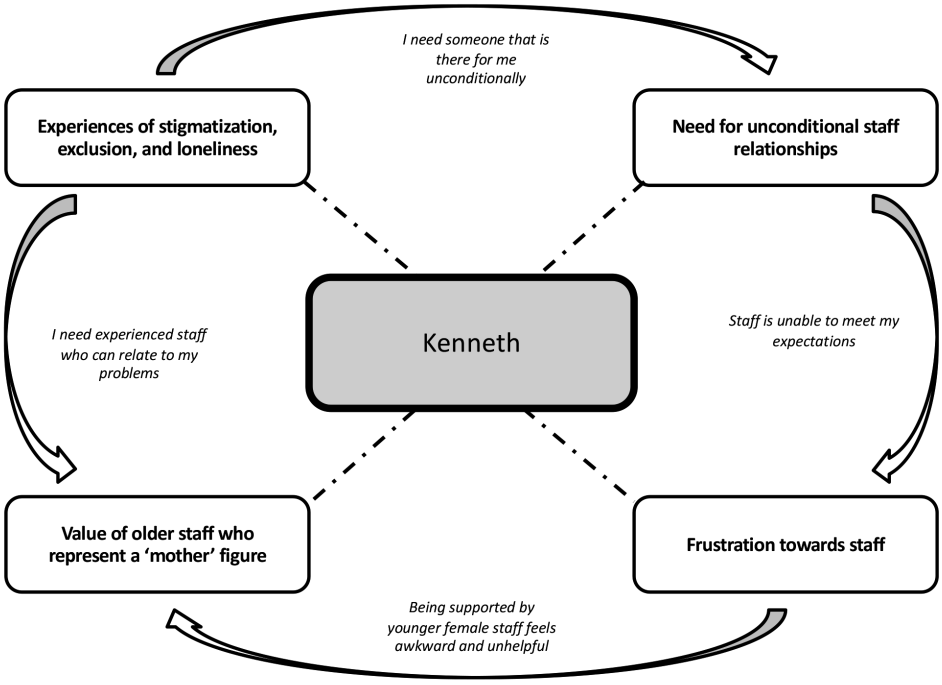

Figure 1. Kenneth's story

"Listen, we all live here together in order to have a good life. And one person might be good with his hands while another is good at thinking. You see, we cannot all be the same. That would be something. And I am content. I am not ashamed of what is wrong with me." (Kenneth)

Thomas, Lynn, Daniel and Jill did not speak about struggles with identity or the acceptance of disability and their need for support. Thomas stated that he had got used to the fact that he needed to live with support, because it had been this way since he was a child.

"Yeah I have got [professional] support since I was very young, so I have got used to it by now." (Thomas)

It seemed that, in his experience, the need for support just reflected the way his life was, as he talked about how he could not imagine a life without staff support.

A Life of Support, Putting the Pieces Together – Kenneth's Story

When presenting the themes separately a sense of their overall meaning in relation to individual participants' lives can be lost. Hence this last brief section focuses on Kenneth and how the different themes relate to each other in his particular case, as illustrated in Figure 1.

Kenneth was frustrated by his relationships with staff. These feelings seemed to be related to his experience of stigmatization, exclusion, and loneliness. As a result of these experiences, it was vital for him to have someone who was there for him unconditionally and Kenneth wanted to have close, personal relationships with staff. However, as staff could be formal in their approach, they failed to live up to his expectations. He disliked being supported by younger female staff, as it felt awkward to talk to them about his problems. Instead, he preferred relationships with staff who were older than him and who Kenneth regarded as 'mother' figures. In his experience, they could also relate better to his problems and deal more sensitively with subjects such as intimacy, family and loneliness.

Discussion

This study established an in-depth account of the experiences of six individuals with mild intellectual disability with respect to living with support. Three overarching themes emerged from the analyses: (A) relationships with staff placed within a personal history, (B) relationships with staff within an organisational context, and (C) staff support and interviewees' place in the world. First, our findings showed that to truly understand participants' accounts of relationships with staff, these relationships should be interpreted in the broader context of their social histories. Consistent with previous research, we found that relationships with staff were highly valued by individuals with mild intellectual disability (Van Asselt-Goverts et al., 2013). For the majority of participants, relationships with staff were one of the closest and most significant social relationships they had, with staff not only providing them instrumental support, but also emotional support (Van Asselt-Goverts et al., 2013), and significant and meaningful social contact (Kwekkeboom et al., 2006). In line with previous studies (Bigby, 2008; Pockney, 2006; Mason, Timms, Hayburn, & Watters, 2013), participants described their relationships with staff in a way that included friendship. However, in our study at least one participant was acutely aware of the fact staff did not meet their expectations for friendships and that 'friendships' with staff should not be considered reciprocal. This experience is related to Pockney's (2006) finding that staff and service users often had different perspectives on their shared relationship, as staff seldom considered people with intellectual disability as friends.

The results also showed that relationships with staff played a more central role in the lives of participants when they had few other friendships or close relationships. The informal networks of individuals with intellectual disability are often relatively small (e.g., Forrester-Jones et al., 2006; Lippold & Burns, 2009; Van Asselt-Goverts et al., 2013), also meaning that they may have less access to social capital. Social capital is classically defined as resources that flow to individuals from their possession of a durable social network, reflecting mutual recognition (Bourdieu, 1986). Access to resources such as emotional and material support, and developing trusted social relationships with others, who are on your side and can help you, are associated with better physical and mental health (Kawachi & Berkman, 2001; Kawachi, Kennedy, & Glass, 1999; McPherson et al., 2014; Riumallo-Herl, Kawachi, & Avendano, 2014). For the current sample, having few friends or social relationships appeared to be linked to feelings of exclusion and loneliness. Research suggests that up to 50% of individuals with intellectual disability are chronically lonely, compared to about 15-30% in the general population (Gilmore & Cuskelly, 2014). In common with the participants in the current study, other research has shown that individuals with intellectual disability want to have more friendships and/or an intimate relationship (Friedman & Rizzolo, 2018; Healy, McGuire, Evans, & Carley, 2009; Rushbrooke, Murray, & Townsend, 2014). Living in the community had not necessarily led to increased social capital or meaningful inclusion for the participants in the current study. Instead, staff continued to play a vital role in their social lives.

Societal views that stigmatize individuals with intellectual disability may also limit their opportunities for experiencing social and emotional connectedness and, consequently, increase their vulnerability to loneliness (Gilmore & Cuskelly, 2014). Consistent with earlier work on stigma (Ali, Hassiotis, Strydom, & King, 2012), participants were aware of stigma and described experiences of being treated differently or negatively. Stigmatizing views were viewed by participants as a barrier to forming friendships and intimate relationships with people in the wider community; they experienced a gap between "us" and "them" and talked in terms of "we" versus "they" (cf. Goffman, 1963). In line with Goffman's theory on spoiled identities, stigmatizing views were also related to participants' struggles with their identities. Paradoxically, the help and support they needed to lead their lives was what some participants felt that marked them out as different and, in their experience, "spoiled" their identity. Partly in response to this experience, Kenneth made efforts to refute or distance himself from perceived prejudice or discrimination (Ali et al., 2012; Beart, Hardy, & Buchan, 2005; Jahoda & Markova, 2004, Finlay & Lyons, 2000). Kenneth used downward social comparison, making it clear that he saw himself as different from people with more severe levels of disability and emphasizing his strengths while minimizing his weaknesses (Ali et al., 2012). Our data suggest that stigma theory has relevance when understanding the lives

and identities of people with intellectual disability living in the community.

With respect to societal views, findings suggest that more positive societal views are related to increased social contact with community members (Blundell, Das, Potts, & Scior, 2016; MacMillan, Tarrant, Abraham, Morris, 2014; Scior, 2011). An important role of staff should be to facilitate meaningful social contact with other people in the community. It has been shown that staff usually prioritise care tasks over social support (McConkey & Collins, 2010), even though it has been shown that staff themselves recognize the importance of social support for people with intellectual disability living in the community (Van Asselt-Goverts, Embregts, Hendriks, & Frielink, 2014). Staff may prefer to view themselves as facilitators to friendships, instead of fulfilling a friendship role (Pockney, 2006).

Study participants reported that limited staff time, which has become even more pronounced in times of austerity and service cuts, was a barrier to building relationships with staff and also meant that staff had limited opportunity to help promote their social inclusion. The need for sufficient staff time to meet people with intellectual disability's need for social support has also been highlighted in previous studies (Abbott & McConkey, 2006; Van Asselt-Goverts et al., 2014). Participants also experienced high levels of staff turnover and felt that a lack of continuity was another barrier to building close relationships with staff and may have prevented staff from developing good insight into their support needs. High staff turnover also meant that participants frequently experienced a personal loss of valued relationships. However, maintaining one trusting, longer lasting relationship with a key worker did appear to help some participants deal with staff turnover in their support team.

The results of the current study were consistent with existing research and added to the literature by exploring in detail what individuals with intellectual disability thought and felt with regard to support from staff and, more broadly, their experience of living with support. Our study showed that the experiences of individuals with intellectual disability varied widely when it comes to living with support and their social relationships with, for example, friends and family. Therefore, it is important that support is attuned to the needs of each person. Not all staff have to fulfil the same role for each individual person, as participants displayed preferences for staff members with whom they had developed a trusting or closer relationship. It is important for staff to acknowledge that people with intellectual disability will have preferences for people they get on better with. There were, however, some limitations of the study. In line with the IPA method, this study focused on the experiences of only six participants and the generalizability of the findings to the wider population of individuals with intellectual disability is unknown. More specifically, our findings concerned individuals receiving 24 hour support in the community in the Netherlands. As support arrangements vary both

within and across countries, future research might address support experiences of individuals with intellectual disability in different kinds of support arrangements in various countries to consider possible differences in experiences. Finally, even though we aimed to establish in-depth accounts of participants' support experiences, Jill's interview lasted only 18 minutes (despite the attempts of the interviewer to build rapport before and during the interview). However, the way Jill interacted with the interviewer and the way she spoke in a brief forthright fashion about her support experiences, was consistent with her narrative about a lack of trust in staff and a tendency to withdraw herself from them.

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CHAPTER 3

3

Measuring emotional support in family networks: Adapting the Family Network Method for individuals with a mild intellectual disability

This chapter has been published as:
Giesbers, S. A. H., Tournier, T., Hendriks, A. H. C., Hastings, R. P., Jahoda, A., & Embregts, P. J. C. M. (2019). Measuring emotional support in family networks: Adapting the Family Network Method for individuals with a mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 32*(1), 94-105.
http://dx.doi.org/10.1111/jar.12512

Abstract

Background
Informal supportive networks of individuals with intellectual disability have become increasingly important. The aim of this paper is to describe how the Family Network Method – Intellectual Disability (FNM-ID) offers a way to gather the perspective of people with mild intellectual disability on their family support.

Method
The FNM is designed to explore how individuals define their family contexts, and more specifically how they perceive existing supportive relationships in these contexts.

Results
By carefully piloting ways of questioning people with mild intellectual disability, systematic adaptations were made to the original FNM. Data obtained by the FNM-ID can be analysed using social network analysis. Thereby, the FNM-ID provides rich, theoretically significant information on emotional support in the family networks of individuals with mild intellectual disability.

Conclusions
The FNM-ID is a useful and successfully adapted tool for other researchers and professionals to systematically explore the family support experiences of individuals with mild intellectual disability.

In recent years, participation and social inclusion have dominated the policy discourse in the field of intellectual disability within western society. To enhance participation and social inclusion, and thereby the quality of life of individuals with intellectual disability (Schalock, 2004), a supportive social network is essential (Simplican, Leader, Kosciulek, & Leahy, 2015). As a result, an emphasis has been placed on forging stronger links with their local community to increase and strengthen informal networks of support (e.g., Hewitt, Nord, Bogenschutz, & Reinke, 2013). In line with these changing societal views, researchers have paid increasing attention to the social networks of individuals with intellectual disability. Several studies have examined the characteristics of their social networks, showing that the networks of the majority of individuals are relatively small (Lippold & Burns, 2009), that friendships are often formed with other people with disabilities and that interactions between individuals with intellectual disability and those in the wider community may be mainly restricted to family members (Forrester-Jones et al., 2006; Robertson et al. 2001; Van Asselt-Goverts, Embregts, & Hendriks, 2013, 2015; Verdonschot, De Witte, Reichrath, Buntinx, & Curfs, 2009).

Even though informal networks of individuals with intellectual disability are found to mainly consist of family members, research on family support provided to them has been scarce. For several decades, research has mainly focused on the impact of having a child with intellectual disability on parental well-being and family quality of life (Hastings, 2016). It has been extensively shown that parental and family outcomes are influenced by many factors such as child characteristics, parents' cognitive styles, and family and environmental features. More specifically, social support, especially support from family members, is an important contributing factor to positive outcomes for parents of a child with intellectual disability (Canary, 2008; Cohen, Holloway, Domínguez-Pareto, & Kuppermann, 2014; Hassall, Rose, & McDonald, 2005; Hastings, Allen, McDermott, & Still, 2002; Shin, 2002; White & Hastings, 2004). However, studies on the provision of family support including directly the perceptions of individuals with intellectual disability have been rare. Research has shown that the actual amount of support may be of less importance for positive outcomes than the supported person's perception of the helpfulness of the support (Shin, 2002; White & Hastings, 2004), which also highlights the necessity of directly exploring the support experiences of individuals with intellectual disability themselves (Embregts, 2011; McDonald, Kidney, & Patka, 2013). Within the literature, support is often differentiated into emotional and instrumental support. Perceived emotional support is regarded as the most significant type of support and found to be a stronger predictor for positive physical and mental health related outcomes than instrumental support (Berkman, 1995; Thoits, 1995; Viswesvaran, Sanchez, & Fisher, 1999). Also, people have been found to attribute an emotional meaning to supportive behaviours that are instrumental in nature. In other

words, by providing instrumental support someone may show that they are being caring and have an understanding of another person's needs (Semmer et al., 2008).

Various instruments have been used to examine social network characteristics of individuals with intellectual disability, such as the Social Network Map (Robertson et al., 2001; Tracy & Abell, 1994), the Social Network Guide (SNG; Forrester-Jones et al., 2006), the Social Support Self Report (SSSR; Lippold & Burns, 2009; Lunsky & Benson, 1997), the Social Network Questionnaire (Dagnan & Ruddick, 1997; Krauss & Erickson, 1988), the Support Interview Guide (SIG; Llewellyn & McConnell, 2002), the Functional Support Inventory (FSI; Felton & Berry, 1992; Lippold & Burns, 2009), and the Hierarchical Mapping Technique (Circles Task) (Antonucci, 1986; Lippold & Burns, 2009). Using these existing instruments, researchers have been able to provide detailed information on social network characteristics, including the views of individuals with intellectual disability themselves. The instruments were used to examine the supportive relationships that existed between the person with intellectual disability and his/her network members. Most of these instruments focused on support received by the person with intellectual disability (Antonucci, 1986; Dagnan & Ruddick, 1997; Felton & Berry, 1992; Llewellyn & McConnell, 2002). Some instruments (i.e., Social Network Map, SSSR, and the SNG) also examined the support that was given by the person with intellectual disability to his/her network members, assessing the reciprocal character of the person's supportive relationships (Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001).

However, none of the existing social network instruments have examined the supportive relationships existing among all network members of the person with intellectual disability. Relationships between a person and his/her network members cannot be seen as isolated from the broader social context. Until know, research has often disregarded the social context of interdependencies among network members of individuals with intellectual disability in which, for example, intimate relationships, close friendships, or parent-child relationships are embedded. In addition, none of the methods listed above have a specific focus on assessing the family networks of people with intellectual disability – although all would potentially capture elements of support from family members.

An instrument that has been developed to explore how individuals define their family contexts, and more specifically how they perceive existing supportive relationships in these contexts, is the Family Network Method (FNM; Widmer, Aeby, & Sapin, 2013). In line with a trend in sociological research, the FNM has conceptualized family relationships within the theory of social capital (Furstenberg & Kaplan, 2004; Widmer, 2006, 2007, 2016). Social capital is defined as resources that flow to individuals from their membership of a durable social network (Bourdieu, 1986). From this perspective,

family relationships (i.e., family-based social capital) are expected to have a variety of positive outcomes for the individual, such as promoting physical and mental health (Kawachi & Berkman, 2001; Kawachi, Kennedy, & Glass, 1999; McPherson et al., 2014; Riumallo-Herl, Kawachi, & Avendano, 2014). The main types of social capital, bonding and bridging social capital (Coleman, 1988; Burt, 1995), are relevant with respect to family networks. Bonding social capital refers to network closure (i.e., a group with a high density of connections and redundant ties) (Coleman, 1988). As dense networks enhance expectations, obligations, and trust among its members, support within such a network becomes collective. Traditionally, family relationships have been regarded as bonding social capital, based on the assumption that the significant family is constituted by the nuclear family (i.e., married couples and their children). However, this focus on the nuclear family ignores the fact that, due to the pluralization of life courses in late-modernity, family contexts have become more heterogeneous and open (Allan, 2008; Widmer, 2016). More recently it has been shown that family contexts based on blood ties mostly provide a bonding type of social capital, whereas family contexts based on friendships usually provide bridging social capital (Widmer, 2006, 2007). Bridging social capital refers to weaker connections between subgroups of a network that give some individuals (i.e., brokers) the potential to mediate the flow of resources between group members (Burt, 1995). To examine the social capital that is provided by the family, FNM respondents are not only asked about their own relationships with family members, but also about their views of relationships amongst the different family members who make up their network. Thereby, the FNM provides a better understanding of the family context of structural interdependencies in which individuals and their close family relationships are embedded. As the FNM captures respondents' perceptions of how their family networks are organised in terms of, for example, support provision, the FNM might be a useful instrument to question individuals with intellectual disability about their family support experiences, thereby examining the social capital their families provide.

However, the FNM was developed for use in the general population. Although there is evidence that individuals with a mild intellectual disability can be reliable informants of their support experiences (Lunsky & Benson, 1997), the instrument cannot be automatically applied to them. As a result of cognitive and language impairments, they might experience difficulties in understanding questions and communicating valid and reliable answers when using instruments developed for people without disabilities (Coons & Watson, 2013; Finlay & Lyons, 2001). Yet it has been generally recognized that individuals with intellectual disability have a valid perspective on their lives and several suggestions for questioning them in a reliable and valid way have been made in the literature (Perry, 2004). The FNM has previously indeed been used with individuals with

mild intellectual disability (Widmer, Kempf-Constantin, Robert-Tissot, Lanzi, & Galli-Carminati, 2008; Widmer, Kempf, Sapin, & Galli-Carminati, 2013). However, the exact procedure that has been used to question them has not been reported. To enhance the method's transparency and transferability for use in the population of individuals with intellectual disability, it is important to systematically report the procedures used and to document the adaptations that have been made to facilitate their understanding. Therefore, the first aim of this paper is to describe how systematic adaptions have been made to the FNM, by carefully piloting ways of questioning individuals with mild intellectual disability about their family networks, making the FNM a useful and reliable tool for other researchers and professionals. The second aim of this paper is to give a detailed description of the data that could be obtained by the FNM.

The Original Family Network Method

The original FNM consists of three parts, a detailed description is shown in Table 1. In the first part, participants are asked to list their significant family members. The term 'family member' is deliberately left undefined, to allow participants to decide whom they consider as family and may wish to include as significant family members. Participants are told that the term 'significant' refers to those family members who have played a role in their life, either positive or negative, during the past year (Widmer, 2006). In the second part of the FNM, participants are asked about their perceptions of the relationships between the family members they have identified. Four aspects of the relationships between family members are examined: emotional support, instrumental support, influence, and conflicts. In the third part, socio-demographic information is collected about each listed family member, as well as information on the nature of the family tie, the duration of the relationship, and the frequency of contact.

Family Network Method – Intellectual Disability: Revised Content and Procedures

To adapt the FNM for use with individuals with intellectual disability, two pilot studies were carried out, involving a total of 19 participants with a mild (n = 16) or moderate (n = 3) intellectual disability. Participants had a mean age of 32.7 years (SD = 13.14, range 19 – 65 years) and 13 were male. The vast majority (n = 13) of participants lived in community based settings, whereas 6 lived in residential, more segregated, facilities. This early testing suggested that asking people with intellectual disability about multiple dimensions of support would be overly complex and may not lead to different information for each dimension. For example, difficulties arose in differentiating

instrumental from emotional support. The nature of the wording might not have been understood by people with intellectual disability when trying to explain instrumental support. Also, piloting showed that focusing only on emotional support already placed a high time demand on participants. Since perceived emotional support is also regarded as the most significant type of support (Berkman, 1995; Thoits, 1995; Viswesvaran, Sanchez, & Fisher, 1999), the initial question about family relationships focussed on emotional support only. Therefore, during the pilot interviews, participants were asked to examine the relationships among their family members in relation to emotional support provision: 'Who would give emotional support to X [i.e., each individual included in the participant's family configuration, considered one by one] during routine or minor troubles?' (Widmer et al., 2013).

Before the pilots were carried out by the first two authors of this paper, the original FNM was translated into Dutch using a systematic forward-backward translation procedure (Cull et al., 2002). In addition, instructions for the interviewer were added to standardise the interview procedure. During the pilot interviews, one researcher was the interviewer, the second researcher observed and made notes about the procedure and difficulties that occurred during the interview. After the interview, these notes were documented in a log. The duration of the interviews varied between 15 minutes and two hours, depending on how many family members were listed, and the participant's understanding of the questions, which varied according to their level of intellectual disability and ability to concentrate. Based on the experiences of these pilot interviews, as well as the suggestions of Finlay and Lyons (2001) about overcoming difficulties when interviewing people with intellectual disability, adaptations were made to the original instrument.

Interview Procedure

The FNM-ID is carried out individually with the participant at a place of their choosing, to ensure the participant's privacy and to facilitate a congenial atmosphere which might contribute to a feeling of safety. At the start of the interview, the interviewer initiates "small talk" with the participant, in which specific questions about the family network are asked. For instance, questions with respect to significant others in the participant's living situation, leisure time, and work. This small talk helps to make the participant feel comfortable and allows the interviewer to develop a picture of the participants' life and gain an initial insight into significant others in his/her network. The interviewer is able to start with the first question of the FNM-ID after observing that the participant is at ease. The first question of the FNM-ID is to talk about the family network.

1. I would like to talk to you about your family. You define for me who you consider to be your family.
   Could you tell me about your nuclear family? Who is in your nuclear family?
   Could you tell me about your extended family? With whom do you have contact (in some way)?

The interviewer writes all the names of the listed family members down on separate cards, starting with the name of the participant. On every card, a number is written as well (the participant is always number one, the first listed person is number two, the second listed person is number three, etc.), which corresponds with the number on the scoring form. If the participant mentions demographic information when talking about a person, the information is noted on the back of that person's card. The interviewer tells the participant that the names of listed family members will not be used for research; every single person receives a code after the interview and the data are processed anonymously.

The second question is about defining the significant family members from those listed at the first stage:

2. Which members of your family are significant to you? It could be no-one, a few or all of them, it is up to you how many people you choose.
   2.1. Who among them means a lot to you?
   2.2. Who is always there for you?

The interviewer checks whether the family members on the cards are considered to be significant by showing the cards (one by one) to the participant. A green and a red box are used to support the participant; cards for family members who are considered significant are put in the green box, the cards of the family members who are considered not significant, are put in the red box. Alternative questions (for example question 2.1 and 2.2) can be asked (in a fixed order) when a participant is not able to answer the main question. If these additional questions are not sufficient, strategies can be used to help participants to answer the question (see Table 1). These questions and strategies were added to standardise the procedure of the FNM-ID and to enhance the reliability of the instrument. Subsequently, all the cards in the green and red box are put back on the table again and the interviewer moves on to the third question, which is about emotional support. This question concerns whether a participant receives and/or gives emotional support to his/her listed persons; and whether emotional support is provided among all the listed people.

3. If X is feeling out of sorts, who is there for X?
   3.1. If X is not having such a good day, who supports X?
   3.2. If X is feeling out of sorts, who listens to X?
   3.3. If X is feeling out of sorts, who reassures X?

The interviewer checks whether the family members give emotional support to the participant by showing the cards (one by one) again to the participant. Again, the red and green box are used to support the participant and additional questions are available. After this is completed, the participant is asked to provide his/her perceptions of the relationships among the network members, answering the same questions about emotional support for every single person (using the same procedure with the cards and the boxes). If the main question or the additional questions are not sufficient to obtain answers, strategy C can be used (see Table 1). After this, demographics of all the listed people are collected and written on the back of the card of the concerning person. Table 1 provides an overview of the demographic data collected.

Finally, a fourth question about significance of the participant to his/her family members is asked:

4. To which of your family members are you significant? It could be no one, a few or all of them, it is up to you how many people you choose.
   4.1. To whom do you mean a lot?
   4.2. For whom are you always there?

The interviewer checks whether the participant considers themselves significant to every family member in the network by showing the cards of all members (one by one) to the participant. Again, additional questions (4.1 and 4.2) are available in case the main question is not sufficient and the boxes are used.

Based on these two pilots, Table 1 summarises, per topic, the adaptations and rationale of adaptations between the original FNM and the FNM-ID.

Table 1. Original FNM and FNM-ID: Description, Differences and Rationale for Adaptations

Topic	Original FNM	FNM-ID	Rationale for adaptations
FNM guide in general	Names of family members are written down on a list.	- Cards are used to write down the names of the family members - Demographics are written on the back of the cards - Green and red boxes are used to differentiate first between significant and not significant family members and later between family members who provide support and those who do not provide support.	Supportive (visual) techniques were added to the protocol. According to Boster (1994) a card sorting method makes it easier to judge the similarities among large numbers of items. The names of the listed family members were written down on small paper cards (one card for each person) so they can be presented on the table to give a better overview of the listed family members compared to writing down a list of names. As demonstrated in earlier studies (e.g., Forte, Jahoda, & Dagnan, 2011; Pownall, Wilson, & Jahoda, 2017), asking the participants to select and post the cards helped to scaffold their task and ensure they were making active judgements. Also, the cards put the participant more in charge of the decision making. A red and a green box were used to support answering the questions and to ensure participants are making active choices and to make the choice more tangible.
Start of the interview	Officially not in the original FNM guide	- Start small talk with the participant. Specific questions about the family network are asked. For instance, significant others in the living situation, leisure time or work.	
Introductory talk about family	Officially not in the original FNM guide	1. Talk about the family network, give instruction and ask the two following questions: I would like to talk to you about your family. You define for me who you consider to be your family. - Could you tell me about your nuclear family? Who is in your nuclear family*? - Could you tell me about your extended family? With whom do you have contact (in some way)? *In Dutch the word "gezin" is used for the nuclear family, a commonly used word, which typically refers to parents and their children. The right terminology in English for individuals with mild intellectual disability needs some further thought.	During the pilot the researchers noticed that participants would think more about family members they recently saw or spoke to instead of their whole family. Therefore, an introduction to the FNM was added, in which participants were asked to talk about their family. The aim of establishing rapport and opening up the topic of family more broadly was to ensure that participants would think about their whole family when answering the question 'who is in your family?' and not just people they saw lately. Also, the instruction 'you tell us who you think of as family' was added to the first question because the researchers were interested in finding out about the participants' own definition of family.

Table 1. Continued

Topic	Original FNM	FNM-ID	Rationale for adaptations
Defining significant family members	Respondents are first asked to give a list of persons that they consider as significant family members. They are instructed that the term 'significant' refers to those people in their family who have played a role, either positive or negative, in their life during the past year. A statement is read to respondents that further emphasizes that they should not only refer to the people of their family who are significant to them because they love them or respect them, but also to those who have upset them or have made them angry during the last year. The term 'family' is left undefined and respondents are asked to use their own definition of what they intend by 'family'.	2. Define the significant family members: 2.1. Which members of your family are significant to you? It could be no one, a few or all of them, it is up to you how many people you choose. 2.2. Who among them means a lot to you? 2.3. Who is always there for you? **Strategy A:** - Ask the participant permission to take a picture of him/her. - If 'yes': Take a picture and print this picture. If 'no': A pictogram of a man/woman is shown to the participant. The interviewer explains that the image represents the participant. - The participant is asked to put the cards of the family members that are most significant/closest to the participant next to the image. - If the participant is not able to indicate the most significant people, ask for the most significant five. - If the participant is not able to indicate the most significant five people, ask them one by one (e.g. who the foremost significant person is / who is number one, who else is significant?) **Strategy B:** - Ask the participant about a significant event. - Ask the participant: if this event takes place, who of your family members should definitely come/be there? - If the participant is not able to list the most significant people, ask for the most significant five. If the participant is not able to list the most significant five people, ask them one by one (e.g. who is foremost significant person / who else etc.)	We noticed that the explanation about 'significant family members' was too complicated and confusing for people with intellectual disability. Participants asked for further explanation before they were able to answer the question. Therefore, the explanation about 'significant' family members ('Significant refers to people who have played a role, either positive or negative, in your life during the past year') was omitted from the adapted approach, enabling participants to give their own interpretation of significance. When defining the significant family members, the instruction 'it could be no one, a few or all of them, it is up to you how many people you choose" was added. During the second pilot, the interviewers experienced that participants sometimes already made a selection when listing their family members (i.e., participants did not list their whole family but just a selection of significant members). By adding the instruction that all family members could be considered significant, the researchers tried to avoid over-selecting significant family members. Furthermore, the instruction that none of the family members could be considered significant is added to decrease the chance of social desirable answers.

Table 1. Continued

Topic	Original FNM	FNM-ID	Rationale for adaptations
Emotional support	Who would give emotional support to X during routine or minor troubles? (E.g.: when X is sad, when X had a bad day, who would help him/her, console him/her, etc.) (The original FNM asks these questions only about significant family members).	3. Defining the emotional support of relationships: 3.1. If X is feeling out of sorts, who is there for X? 3.2. If X is not having such a good day, who supports X? 3.3. If X is feeling out of sorts, who listens to X? 3.4. If X is feeling out of sorts, who reassures X? **Strategy C:** - Ask: Does X ever feel out of sorts? Ask the participant to think back and tell about the last time that happened. Ask about the persons who supported X in that situation. Ask about persons who help X in similar situations.	
Demographic questions	- Gender - Age - Level of education - The nature of the family tie - The duration of the relationship - Where does the person live - Frequency of contact face-to-face - Frequency of contact in other ways (telephone, internet)	- Gender **Is X male or female?** - Age (categorised into decades) **How old is X?** - Nature of the family tie **What is your family tie with X?** - Duration of relationship → only if the participant lists someone who isn't a family member (categorised into decades) **For how long have you known X?** - Place of residence **Does X live in the same village/city as you?** - Frequency of contact (categorised: every day, every week, every month, less than once a month) **How often do you see X face-to-face?** **How often do you have contact with X in other ways? (Telephone, internet).**	Answering the questions about demographics was found to be difficult for people with intellectual disability. The researchers noticed that participants were not able to answer the questions precisely which, in some cases, made them feel insecure and irritated. Since a rough estimation about these characteristics is sufficient enough, categories were made for the demographic questions about age, duration of the relationship, place of residence and frequency of contact. The question about level of education of family members appeared to be too difficult to answer for most participants, therefore it was decided to eliminate this question.
Significance of the person with ID	Officially not in the original FNM guide	4. Defining significance of the person with ID to the family members: 4.1. To which of your family members are you significant? It could be no-one, a few or all of them, it is up to you how many people you choose. 4.2. To whom do you mean a lot? 4.3. For whom are you always there?	Since it might also be valuable to measure another element of the reciprocity of significance within relationships, a new question was added at the end of the interview; the participant is asked to whom they thinks they are a significant other.

Social Network Measures Obtained from the FNM-ID

In this part of the paper, we will illustrate the measures that give insight into people with mild intellectual disability's perceptions of their family configurations, based on the data obtained from the FNM-ID. As in the original FNM, analysis concerns the significant family network (family members that are selected at step two of the FNM-ID). Different software packages can be used to analyse social network data, for example UCINET (Borgatti, Everett, & Freeman, 2002) or R software packages like statnet (Handcock, Hunter, Butts, Goodreau, & Morris, 2016). Using these packages, measures can be calculated for the significant family network of the participant as a whole (network measures) or for specific persons in the network (centrality measures). Network measures give a better understanding of family configurations of people with mild intellectual disablity, whereas centrality measures give information about how individual family members are located or embedded in the overall family network (Hanneman & Riddle, 2005).

1. *Network measures*. Several measures about the family network can be calculated: i.e., size, density, average degree, arc reciprocity, and index of components. The size of the network represents the number of family members listed by the participant. Density of a network can be calculated by dividing the number of supportive ties (connections) among all the family members by the maximum number of potential supportive ties if all the family members were connected. In highly dense connected family networks, most or all family members are connected with each other, providing a bonding type of social capital. Average degree calculates the average number of supportive ties of the family members in a network; it divides the total number of supportive ties that exist in the network by the number of network members The arc reciprocity represents the proportion of reciprocal relationships within a network: of all the support that is given from one family member to another, what proportion is reciprocated? The 'index of components' measures how many subgroups there are in a network.
2. *Centrality measures*. Per family member, centrality measures can be computed, qualifying the position of a person in a network. The degree centrality of a family member refers to the number of supportive ties a person has. This measure can be specified as in- or out-degree. The in-degree of a person is the number of supportive ties that represent the support received from other family members. The out-degree is the number of support ties in which a person gives support to other family members in the network. Betweenness centrality describes the intermediary position of a person in the family network. Betweenness centrality is about how many pairs of family members would have to go through to the person in order to reach one

another (in the minimum number of hops). Family members with a high betweenness centrality mediate the flow of support among network members, providing a bridging type of social capital.

3. *Attribute measures*. The FNM-ID obtains demographic information of all the listed family members and the person with intellectual disability: these data are called attributes. Attributes are calculated for either the full family network (e.g., 40% of the family network is male) or the nodes' in- or out-degree (e.g., 10% of the people who provide support live in the same place of residence).
4. *Graphs.* Networks can be visualised using a variety of software methods including NetDraw (part of the UCINET software package). The network and centrality measures can be combined with attributes, and can be visualised by using different colours, shapes or sizes.

FNM-ID Networks: Two Illustrative Cases

Two cases have been selected to illustrate possible differences between family configurations of people with mild intellectual diability and the potential utility of the FNM-ID. Pseudonyms are used to protect anonymity. The first case describes the family configuration of a 27 year old male (Bob) living in the community in the Netherlands. He received support within a clustered care setting and had set times for one-to-one support, but he was able to ask for additional support at any time during a 24 hour period. This participant listed five family members at step one of the FNM-ID; his father, mother, and three uncles. According to Bob, two of his uncles did not have an emotional support connection to anyone in the network (no arcs are pointing to or from the uncles). Bob only considered his parents as significant (see Figure 1). The size of Bob's significant network was three (see Table 2) ; Bob, his father, and his mother who were also the members who provided him with emotional support (the in-degree measure for Bob was 2). Bob was not supporting his parents in return (out-degree measure is 0, arc reciprocity is .00) As there are no reciprocal supportive relationships in the significant network, the density has a score of .50.

Due to the little support among the family members the average degree of the network is 1.00. The betweenness centrality for Bob is .00, indicating that he is not an intermediary for the other network members.

The second case is of a 33 year old female (Mary), also living in a clustered care setting in the community in the Netherlands. At step one of the FNM-ID she listed her mother, father, two sisters, two brother-in-laws, and her two nephews. Except for one brother-in-law, Mary considered all of them as significant, making the size of the significant network eight. Mary has a quite dense network (Figure 2). Figure 2 shows that Mary has

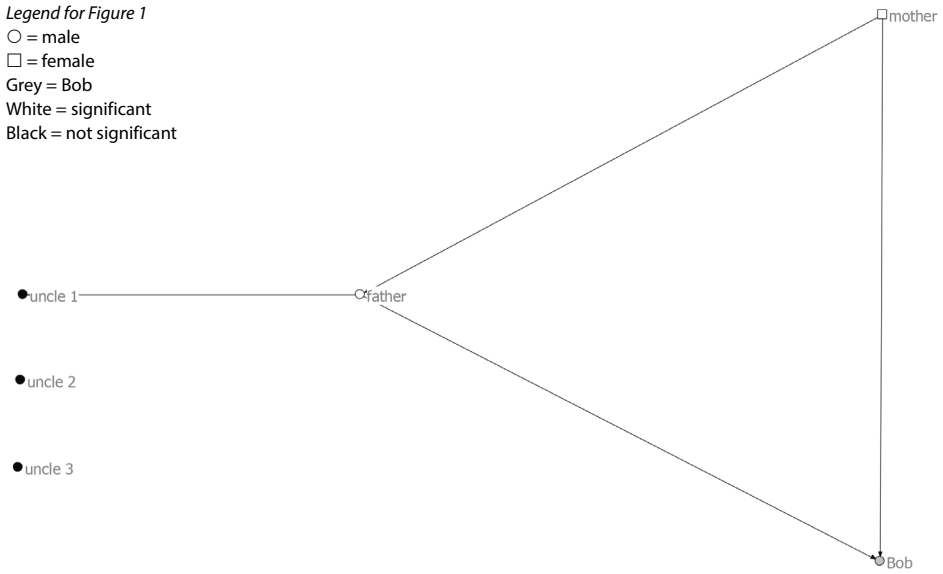

Figure 1. Family configuration for Bob

Table 2. FNM-ID Significant Network Measures for Bob and Mary

Measure	Bob	Mary
Network size	3	8
Density	.50	.661
Average degree	1.00	.625
Arc reciprocity	.00	.703
In-degree	2	4
Out-degree	0	3
Betweenness centrality	0	0

three emotional relationships that are reciprocal (see two sided arcs); with her mother and with her two sisters. Her father is giving her emotional support as well, but Mary feels that she is not supporting him. According to Mary, the other listed family members are emotionally supported by other family members. For example, her mother is supported by the father, sister 1 and 2, Mary herself and brother in-law 1.

As a result of the large number of supportive relationships between the family members, the density score of this network is .66 (Table 2). As previously indicated, the density can be calculated by dividing the number of ties (connections) among the nodes by the maximum number of potential ties. As a result, the score will always vary between

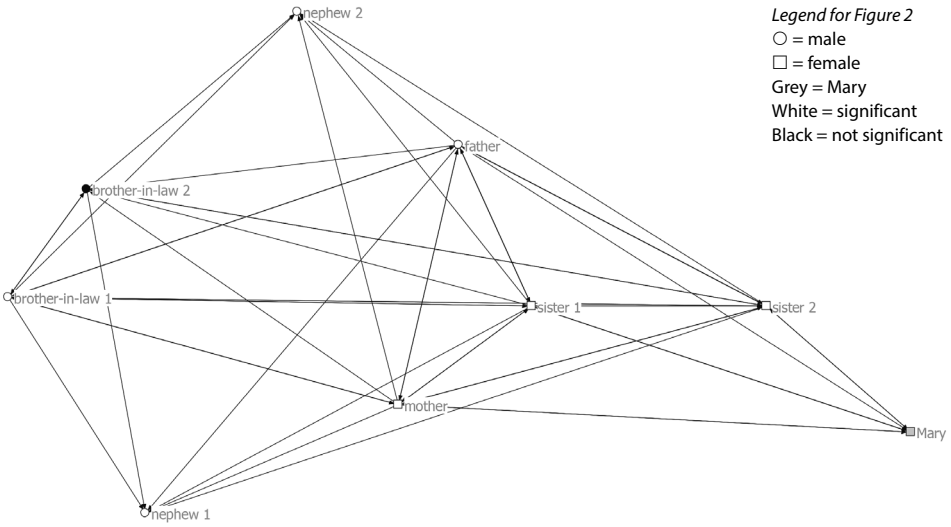

Figure 2. Family configuration for Mary

0 (no support between family members) and 1 (all family members are supporting each other). Therefore, a score of .66 indicates a relatively high density. Because of this supportive network, the average degree is 4.63, and many of these supportive relationships are reciprocal (arc reciprocity is .70). Mary has a betweenness centrality of .00, meaning that no family members have to pass her to reach one another.

In addition to information about the size of a network and the supportive relationships between the family members, the attributes of the family members can also be analysed. Attributes can be, for example, age, gender, place of residence or nature of the family tie and can be calculated by the 'composition'. In Table 3, the network compositions with respect to the attribute 'nature of the family tie' for Bob and Mary are shown. The 'raw score for the whole network' represents the number of each type of family member within the significant network of the person with ID. Bob's network includes two parents (proportion of 1.00) and receives support from both them (proportion is 1.00)(in-degree). This network composition shows that Bob is highly dependent on his nuclear family when it comes to emotional support. This information might be valuable, for example, to understand the sustainability of his family network; when his parents pass away, there will be no other network members available who have a history of providing Bob with emotional support.

Mary's network consists of two parents, two siblings, two extended family members and one in-law family member (see Table 3 for proportion scores). Mary is supported by her two parents and two siblings and provides support (out-degree) to one parent

Table 3. Significant Network Composition Attribute 'Nature of the family tie' for Bob and Mary

Attribute	Participant		Whole network raw score (proportion)	In-degree raw score (proportion)	Out-degree raw score (proportion)
Nature of the family tie	Bob	Parent	2 (1.00)	2 (1.00)	0 (.00)
	Mary	Parent	2 (.29)	2 (.50)	1 (.33)
		Sibling	2 (.29)	2 (.50)	2 (.67)
		Extended family	2 (.29)	0 (.00)	0 (.00)
		In-law family	1 (.14)	0 (.00)	0 (.00)

and two of her siblings. Again, this composition shows Mary's vulnerable position in the family network. If her parents pass away, only 50% of her emotionally supportive family relationships will remain.

Conclusion

The FNM-ID enables a systematic exploration of the way in which individuals with mild intellectual disability define their family contexts, as well as the social capital these contexts provide. Research has neglected the direct perspectives of individuals with intellectual disability with respect to family support. Their informal supportive networks, which to a great extent are shaped by family members, have become increasingly important in a time of austerity and cuts to services. Therefore, gaining insight into their family context may play an important role in facilitating their social participation and inclusion.

Based on thorough piloting, the original FNM has been successfully adapted to better suit the cognitive and linguistic needs of individuals with mild intellectual disability (Finlay & Lyons, 2001). Although the intention was to include people with a moderate intellectual disability in these developments, in our piloting the instrument remained too complex despite the adaptations. In particular, these participants found taking the perspective of another family member too complicated and cognitively challenging. This finding might be due to the degree of their disability. Future research should explore ways of questioning people with moderate intellectual disability about their family networks.

The FNM-ID not only offers a way to gather the perspective of people with mild intellectual disability about their family support, but also provides rich, theoretically significant information about their family networks. In addition, the FNM-ID provides information about the person's perception of the relationships amongst all family network members. Thus, the FNM-ID provides a broader understanding of the family

context of structural interdependencies in which individuals with mild intellectual disability and their close family relationships are embedded (Widmer et al., 2013). Findings of earlier family research has already shown that supportive relationships between a person with intellectual disability and his/her family members cannot be seen as isolated from the broader family structure. More specifically, higher levels of social support for parents of children with a disability, especially support from family members, lead to more positive outcomes in those parents, who in turn, might better relate emotionally to their children (Boyd, 2002; Hastings, Thomas, & Delwiche, 2002; Trute, Worthington, & Hiebert-Murphy, 2008).

After systematically adapting the FNM for use with individuals with mild intellectual disability, the next step is to apply the FNM-ID in research in which substantial samples of individuals with mild intellectual disability are questioned about their family contexts. This is crucial to generate new knowledge on, for example, patterns of family configurations of individuals with mild intellectual disability, the type and amount of family-based social capital available to them, and the relationship between family resources and outcome measures such as the individual's subjective well-being and mental health.

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CHAPTER 4

4

Social capital and the reciprocal nature of family relationships: The perspective of individuals with mild intellectual disability

This chapter has been accepted for publication as:
Giesbers, S. A. H., Hendriks, A. H. C., Hastings, R. P., Jahoda, A., Tournier, T., & Embregts, P. J. C. M. (in press). Social capital and the reciprocal nature of family relationships: The perspective of individuals with mild intellectual disability. *American Journal on Intellectual and Developmental Disabilities.*

Abstract

Even though family plays a significant role in the lives of individuals with intellectual disability, little research has included their own views about their families. This study examined how 138 people with mild intellectual disability describe their family group, with a focus on the reciprocal nature of the emotional support in relationships with family members. Participants reported "significant" family members beyond the nuclear family, and parents were seen as the main provider of support. Only half of participants had a support relationship with siblings and just 13% of participants reported partners. About 30% of support was reciprocal, and reciprocity varied greatly with the types of family connection (e.g., siblings, peers). Implications for future research as well as practice are discussed.

To enhance social inclusion, there has been recent emphasis on supporting individuals with intellectual disability to forge stronger links with their local community, with the aim of increasing informal social networks of support (Simplican, Leader, Kosciulek, & Leahy, 2015), and reducing support from paid staff. Research on social networks has shown that the informal networks of the majority of individuals with intellectual disability are relatively small and that interactions with people in the wider community are often mainly restricted to family members (Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001; Van Asselt-Goverts, Embregts, & Hendriks, 2013). Family members are also the most significant and main providers of informal support to adults with intellectual disability, along with paid support staff (Sanderson, Burke, Urbano, Arnold, & Hodapp, 2017; Van Asselt-Goverts et al., 2013).

Family clearly plays a significant role in the lives of individuals with intellectual disability. For several decades, research has focused mainly on the impact of having a child with intellectual disability on parental well-being or family quality of life, and understanding the factors that reduce or increase psychological difficulties for family members (Hastings, 2016). Researchers have also considered research questions in the reverse direction – how family members' behaviours, well-being and family relationships may affect individuals with intellectual disability. In particular, individuals with intellectual disability are at increased risk for the development of psychological problems, and factors associated with this increased risk include family dysfunction and parental psychological distress (Dickson, Emerson, & Hatton, 2005; Wallander, Dekker, & Koot, 2006). Several researchers have also addressed the bidirectional nature of the relation between parental and family dysfunction and psychological outcomes for the family member with a disability (Greenberg, Mailick Seltzer, Hong, & Orsmond, 2006; Orsmond, Mailick Seltzer, Krauss, & Hong; 2003). For example, in a longitudinal study, Orsmond et al. (2003) followed 193 families of adults with intellectual disability over a six-year period. They found that initial levels and changes over time of adult behaviour problems predicted changes in maternal well-being, while initial levels and changes of maternal well-being also predicted later behaviour problems of adults with intellectual disability.

Despite the recognition that family is an important context for the development and well-being of children and adults with intellectual disability, very little research has considered directly the perspective of people with intellectual disability about their families. Therefore, the primary aim of the current study was to examine the way in which people with mild intellectual disability perceive the support within their family. As people with intellectual disability are the experts on their own lives, experiences, and feelings (McDonald, Kidney, & Patka, 2013), it is important to build a research programme about how people with intellectual disability conceive of their family as

well as the impact their family has on their lives. Existing research has included a small number of qualitative studies about the family-related experiences and perspectives of people with intellectual disabilities (e.g., Kramer, Hall, & Heller, 2013; Walmsley, 1996; Williams & Robinson, 2001). For example, Kramer et al. (2013) found that reciprocity in sibling relationships seemed to consist of siblings with disabilities enacting their family roles (e.g., unclehood or aunthood) in exchange for their nondisabled siblings providing them access to resources in the community. Their study showed that social capital is a useful theoretical framework in understanding support in family relationships.

Social capital is defined as the resources that flow to individuals from their possession of a durable social network of mutual recognition (Bourdieu, 1986). As families may function as a primary source of social support for all individuals, they are a significant source of social capital (Furstenberg & Kaplan, 2004). From this perspective, positive and supportive family relationships (i.e., family-based social capital) are likely to promote an individual's physical and mental health (Kawachi & Berkman, 2001; McPherson et al., 2014; Riumallo-Herl, Kawachi, & Avendano, 2014). Social capital is about the mutual exchange of supports or resources between individuals (Bullen & Onyx, 1999). Exchange within close relationships such as family is not based on an "immediate return" requirement, but more on the assumption that someone will return the favor at some later point and equivalence or reciprocity will be achieved eventually (Antonucci & Jackson, 1990; Torche & Valenzuela, 2011). However, Gouldner (1960) argued that the norm of reciprocity might not apply to certain groups of people, such as children, the elderly, or people with disabilities. In these cases, reciprocity might fail and the norm of beneficence emerges in which people who are able to assist and support others do so regardless of the recipient's future ability to reciprocate (Gouldner, 1973). Being able to provide support may enhance feelings of self-worth and self-esteem (Forrester-Jones & Barnes, 2008; Liang, Krause, & Bennett, 2001). As such, it has been shown that an over-benefited position with more received than given support may lead to a less positive outcome for the individual in terms of mental health and well-being than more balanced relationships or an under-benefited position (Fyrand, 2010; Thomas, 2010).

Individuals with intellectual disability have also recognized reciprocity as a key feature of significant relationships and emphasized the importance of reciprocity in relation to their self-worth (Milner & Kelly, 2009). Reciprocity is important to them to challenge feelings of dependence and to make them feel useful, though they also felt that they do not often have the chance to reciprocate (Milner & Kelly, 2009). For example, individuals with mild intellectual disability (IQ in the range 50-70, American Psychiatric Association, 2000) may highly value relationships with support staff (Van Asselt-Goverts, et al., 2013; Giesbers, Hendriks, Jahoda, Hastings, & Embregts, 2019). However, as these relationships are often of a unidirectional nature, people with mild intellectual disability

may also express discomfort with these relationships and a wish for reciprocity (Forrester-Jones et al., 2006; Giesbers et al., 2019). These findings stress the importance of access to family-based social capital (i.e., being able to receive and contribute support and to experience reciprocity within the family) for people with mild intellectual disability.

In addition to Kramer's et al. (2013) qualitative study, there has been some published quantitative research focused on the families and supports of individuals with mild intellectual disabilities from a social capital theoretical perspective, using family network methodology developed for the general population. For example, Widmer, Kempf-Constantin, Robert-Tissot, and Galli-Carminati (2008) examined the ways in which 24 individuals with mild intellectual disability, 24 individuals with mild intellectual disability and comorbid psychiatric problems, and a non-clinical sample of 24 students perceive their family group. Family-based social capital was found to be strongly influenced by the presence of intellectual disability. Individuals with mild intellectual disability had less supportive, and fewer supported, family members than individuals without intellectual disability. Also, the family members belonging to their networks were less interconnected in terms of supportive relationships (i.e., lower network density), and their networks contained more disconnected family subgroups. Disconnected subgroups do not have any support relationship with other members in the network (outside the subgroup). These findings were even stronger for individuals with mild intellectual disability and comorbid psychiatric problems (Widmer et al., 2008). In a second study, the composition of the family group of 40 individuals with mild intellectual disability was also found to be distinct from the general population, as spouses/partners and children were often missing (Widmer, Kempf, Sapin, & Galli-Carminati, 2013). However, these findings did not imply that individuals with mild intellectual disability were necessarily isolated from family members, as they had a broader conception of family and social capital, by viewing friends, step-family, and professionals as members of their "family" group. Finally, perceptions about family were also found to be dependent on living situation; for individuals living at home, the nuclear family was most prominent, whereas the perceived family groups of individuals living in community residences included more friends and professionals (Widmer et al., 2013).

Even though existing research and theory emphasizes the need for reciprocal relationships for individuals with intellectual disability, still little is known about how these individuals perceive the reciprocal nature of the relationships within their family groups. As individuals with intellectual disability are the experts and authorities on their lives, experiences, and feelings (McDonald, Kidney, & Patka, 2013), it is also important to gain a broader understanding of the experiences of family support, and to systematically describe how they define their family groups and supportive relationships.

A limited number of quantitative studies (e.g., Widmer et al., 2008, 2013) has examined supportive relationships and social capital in families from the perspective of individuals with mild intellectual disability. However, this previous quantitative work did not address the reciprocal nature of relationships within families, which is, as stated, one of the key features of social capital. In addition, it has not used family network methodology that has been adapted specifically for people with intellectual disability (Giesbers, Tournier, et al., 2019), and has relied on small purposive sampling for exploratory studies. Therefore, the current study builds on previous research by examining quantitatively the way in which individuals with mild intellectual disability define their family group as well as the social capital their families provide in a relatively large sample (n = 138) of individuals with mild intellectual disability. More specifically, the research questions for the present study were: (1) how do individuals with mild intellectual disability define their family, (2) who do they consider to be their "significant" family, (3) what emotional support relationships with family members do they describe, and (4) how do they perceive the reciprocal nature of the emotional support relationships within their family? The current study focused on people with mild intellectual disability, because the family network methodology that has been adapted for use with people with intellectual disability was found to be feasible for people with mild intellectual disability, but not for those with more severe levels of intellectual disability (Giesbers, Tournier, et al., 2019). As family support has been found to be dependent on living situation (Widmer et al., 2013), we focused on one living situation only (individuals with mild intellectual disability living away from their birth family with support from a service provider).

Method

Participants

Inclusion criteria for participants were: 1) mild intellectual disability (IQ 50-70) according to file records, 2) aged between 18 and 40 years, and 3) receiving support from paid staff at least once a week for a minimum of six months. The limit for inclusion was set at 40 years old, since parents of older individuals are likely to be elderly and less able to provide support (Bigby, 2008). As family support is found to be dependent on living situation (Widmer et al., 2013), living with their birth family was an exclusion criterion for participants. A total of 138 individuals with mild intellectual disability (IQ 50-70) participated in the study, and 56.5% (n = 78) were male. Participants' age ranged from 18 to 40 years (M = 28.2, SD = 6.14). Additional demographic characteristics are described in Table 1.

Table 1. Demographics of Participants (*n* = 138)

Variable	% (*n*)	*M* (*SD*)
Gender		
Male	56.5 (78)	
Female	43.5 (60)	
Cultural background		
Dutch	92.0 (127)	
Other	8.0 (11)	
Living setting		
Community-based setting	84.1 (116)	
Facility	15.9 (22)	
Living situation		
Together with other service users	60.1 (83)	
Individually	34.1 (47)	
Together with a partner	3.6 (5)	
Other	2.2 (3)	
Additional diagnoses		
Yes	44.2 (61)	
No	54.3 (75)	
Unknown	1.4 (2)	
Additional diagnoses specified		
Autism	23.9 (33)	
Disorder of impulse- or aggression regulation	7.2 (10)	
Genetic syndrome	5.1 (7)	
Personality disorder	5.1 (7)	
Attention deficit hyperactivity disorder	5.1 (7)	
Attachment disorder	3.6 (5)	
Post-traumatic stress disorder	2.1 (3)	
Other	5.1 (7)	
Physical impairment		
Yes	23.9 (33)	
No	76.1(105)	
Sensory impairment		
Yes	11.6 (16)	
No	88.4 (122)	
Age in years		28.2 (6.14)
Years of living in the housing of a service provider		10.4 (6.10)

Recruitment

After ethical approval was obtained from the Ethical Review Board of Tilburg University (EC-2015.46), participants were randomly selected from five service providers for people with intellectual disability in the Southern part of the Netherlands. A stratified sampling procedure (i.e., stratified by service provider) was used to increase the representativeness of the sample. First, each service provider was asked to identify the total number of their service users who met inclusion criteria. Second, it was ensured that, from each provider, service users who met inclusion criteria were proportionally included in the study (10% from each service provider to reach the target number of about 150 participants). As a result, the number of participants per service provider varied from 14 to 50. See Figure 1 for an overview of the sampling procedure.

Recruitment of participants always took place in consultation with the key support worker. After the aim and procedure were explained by the researcher on the telephone, an information letter was sent to key support workers and they were asked to discuss the letter with the selected service users. This letter included information about the aim and content of the study, the financial reward for participation (ten euro cash), and the confidentiality of the data.

Key workers of 354 individuals who met inclusion criteria were asked to invite them to participate in the study, of which 150 participated (42.4%). In the majority of cases of non-response, the invited person decided not to participate (n = 117, 57.4%). Other reasons for non-response were that, before the person with mild intellectual disability was invited, support staff and/or psychologists advised against participation in the study (e.g., the expected burden was too high; n = 59, 28.9%), or relatives/guardians did not agree with inviting the person to participate (n = 21, 10.3%). In these situations, the researchers decided to respect their wishes and the person with mild intellectual disability was not invited. Another reason for non-response was that some staff were unable to facilitate participation of individuals with mild intellectual disability due to high workload and time constraints, and were not able to cooperate with the researchers (n = 7, 3.4%). For those individuals with mild intellectual disability who were invited and accepted the invitation to participate, an appointment was made at their home or another location they preferred.

Measures

Family networks

The Family Network Method – Intellectual Disability (FNM-ID; Giesbers, Tournier, et al., 2019) was used to question individuals with mild intellectual disability about their family networks. The original Family Network Method (Widmer, Aeby, & Sapin, 2013) was adapted for use with people with mild intellectual disability (Giesbers, Tournier, et al.,

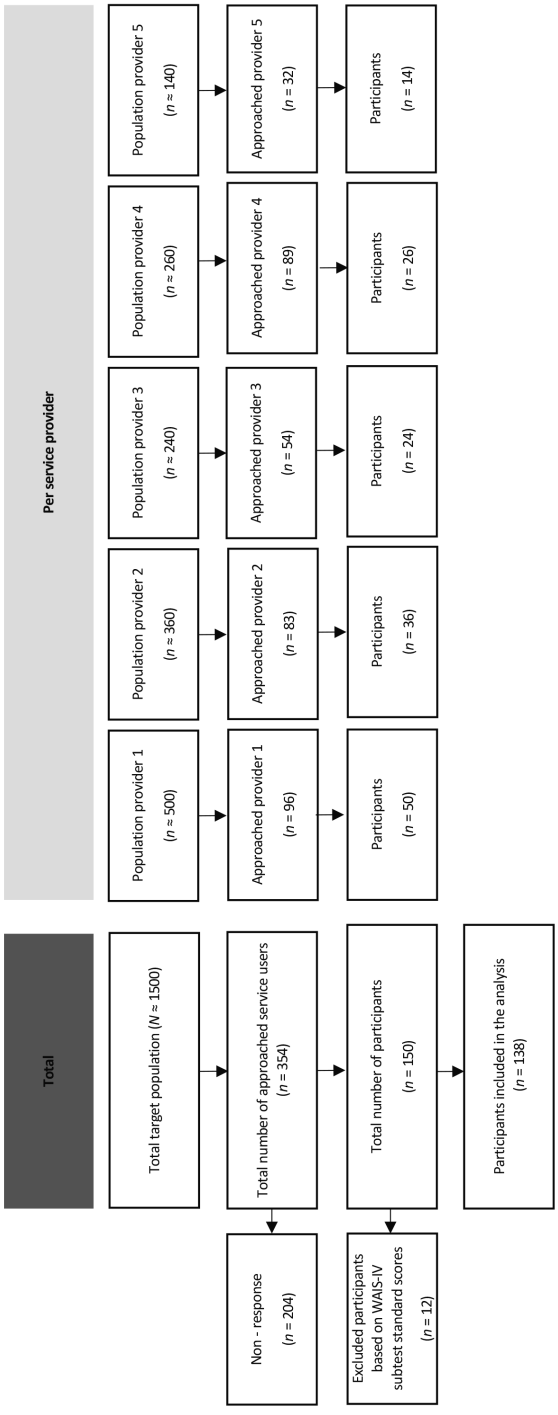

Figure 1. Overview of the sampling procedure

2019). The FNM-ID is a detailed approach, which maps the family network and identifies the significant family members of the participant, as well as the family members who provide emotional support.

The FNM-ID consists of four steps. In the first step, participants are invited to map their family network. The term 'family' is deliberately left undefined by the interviewer; participants are instructed to use their own definition and say who they consider to be their family. The names of all cited family members are written down on separate cards, including a card with the name of the participant. In a second step, participants are instructed to define their significant (according to their own definition) family members from those cited at step one: "Which members of your family are significant to you?" A green and a red box are used to support the participant to make their decision; cards for family members who were considered significant are put in the green box, the cards of the family members who are considered not significant are put in the red box. Alternative formats for this question are used as prompts (in a fixed order) when a participant is not able to answer this main question about significance of family. The third step concerns questions about the provision of emotional support. Participants not only estimate their own relationships with their family members (in terms of emotional support), but also the relationships existing among all family members. That is, after participants are asked who they feel supported by when feeling "out of sorts", the same question is asked for all other members of the family network. For example, participants are asked: "When your brother is feeling out of sorts, who is there for him?". "Feeling out of sorts" is a British translation of the original phrase that we have used in the Dutch language. The original phrase is common, everyday language in Dutch. In addition, alternative formats for the question are available as prompts to facilitate understanding, and the green and red boxes are used to support the participant. In the fourth step, participants are asked to estimate their own significance for other family members: "To which of your family members are you significant?" and the same procedure for alternative prompts, and the green and red boxes, is used. Additionally, key demographic characteristics of all cited family members (e.g., gender, age, place of residence) are gathered.

Cognitive ability

To check whether a participant met the inclusion criterion for the study of having a mild intellectual disability, an estimation of the IQ-scores was made, based on subtest standard scores. The subtests 'Vocabulary' and 'Matrix Reasoning' from the fourth edition of the Dutch Wechsler Adult Intelligence Scale (WAIS-IV; Wechsler, 2012) were used in this study, as these two subtests correspond with the two-subtest form of the Wechsler Abbreviated Scale of Intelligence (WASI-II; Wechsler, 2011). The WASI-II is an abbreviated

version of the WAIS-IV and was developed as a screening tool. However, no Dutch version of the WASI-II was available and therefore the two corresponding WAIS-IV subtests were administered to participants.

Procedure

Data were collected by the first and fifth author, and a research assistant. Participants were visited individually by one of the researchers for approximately 45 to 60 minutes per visit. In some cases (6.7%), the participant was not able to complete all measures during one visit (as they showed signs of distractibility, fatigue, and restlessness, or they themselves indicated that they would like to complete the measures at another time). In those cases, a second visit took place. Each visit started with a brief conversation to put the participant at ease after which participants were asked to give their informed consent. To ensure that participants could give their informed consent, a standard consent procedure was followed (Arscott, Dagnan, & Stenfert Kroese, 1998). After giving participants a verbal and written overview of the research project, the researcher determined whether participants could recall: (i) the general content of the proposed questions; (ii) that they would be interviewed once or twice, (iii) possible favourable and adverse aspects of participation in the study, and (iv) that they would be free to withdraw at any time. If necessary, the researcher explained these four points in more understandable or alternative words until the participant was able to understand the key aspects of the research project. After consent was given, WAIS-IV subtests were administered, according to the prescribed procedure (Wechsler, 2012). Second, demographic characteristics were collected by a computer-administered set of questions. Since it was expected that not all participants were able to read the items, and to maintain the same procedure for all participants, the researcher and participant both sat behind the laptop and the researcher read each item out loud. The participant verbally indicated the response and either the participant or the researcher recorded the response. Participants were then interviewed about their family network using the FNM-ID, following the prescribed interview protocol (Giesbers, Tournier et al., 2019). The FNM-ID interview protocol has been developed by the current authors. As such, the first and fifth author trained and supervised the research assistant in implementing the FNM-ID protocol, and additional supervision and discussion of procedural issues took place throughout the study within the whole research team. In addition, with permission of participants, all FNM-ID interviews were audio recorded. To check for the fidelity of the implementation of the FNM-ID procedure, the three researchers checked 10% of each other's audio recordings of the interviews; no significant deviations from the interview protocol were found. FNM-ID were also audio recorded to ensure that all data were captured. The aim was to establish a conversational tone with the participants,

and it was difficult for the researcher to maintain the natural flow of the questions while writing down all the participants' answers. After completion of all measures, participants received their financial reward. After the visit, with the consent of participants, the researcher contacted the psychologist or key support worker for each participant in order to check for additional diagnoses (official diagnoses according to file records). Also, the scores on the WAIS-IV subtests were converted into standard scores. For 11 participants, both standard scores were indicative of a level of cognitive ability above or below the mild intellectual disability range (taking the standard error into account). Therefore, the data of these 11 participants were excluded from the analysis. This additional check on mild intellectual disability was included in the study because file scores were often missing, outdated, or obtained using unidentified IQ tests.

Data Analysis

Family network data were entered into Excel. Excel files were imported in and analysed using UCINET (Version 6.623; Borgatti, Everett, & Freeman, 2002), a software package for the analysis of social network data. The social network analysis concerned three overlapping sets of family networks: (1) the full family network (i.e., all the listed family members), (2) the significant family network, and (3) the family members perceived by participants as providing them with support (in-neighbourhood; Hanneman & Riddle, 2005), or depending on them for support (out-neighbourhood; Hanneman & Riddle, 2005)(Giesbers, Tournier, et al., 2019). For each set of family members, the size (i.e., number of network members) and the composition (i.e., composition in terms of the nature of the relationship to the participant, such as the number of parents, siblings, and friends that made up the network) were calculated. Also, the direction of support for each of the participant's relationships (received, given, or reciprocal support) was measured. Subsequently, for each type of relationship (e.g., parent, sibling) the proportions of received, given or reciprocated relationships were calculated. Data from the social network analysis for one participant were excluded from further analysis; scores on all but one measures were found to be extreme outliers (three or more standard deviations above the mean).

Results

Definition of the Family

Participants listed a mean of 9.98 (*SD* = 6.28, range: 1 – 34) family members. The most frequent numbers were that family networks consisted of six or seven members (both in 10.1% of cases).

Listed family members were categorized into 12 types based on the nature of the relationship to the participant (e.g., parent, extended family, or friend). See Table 2 for an overview of the composition of family networks of individuals with mild intellectual disability in terms of the nature of the family relationship.

Significant Family Members

On average, participants considered 6.18 family members of the 9.98 full family members to be "significant" (*SD* = 4.86, range: 1 – 26). Seven participants perceived only one family member as being significant (5.1%). Most frequently, participants listed four significant family members (17.4%), and 50.7% of participants listed no more than four significant family members. Participants felt that they were themselves significant to 5.52 (*SD* = 4.87, range: 0 – 26) of their 6.18 significant family members (i.e., mutual significance). Three participants did not feel they were significant to anyone in the network (2.2%), and the modal number was that participants felt mutually significant to four network members (21.2%).

Table 2 also describes the nature of the relationship with the significant family members. Compared to the full family network, the number of times the family member type was listed by participants declined for nearly all categories, except for partners and children, meaning that listed partners and children were always in the significant network.

Table 2. Composition of the Full and Significant Family Network

	Full family network		**Significant family network**	
Type of relationship to participant	% of participants that listed the relationship (*n*)	Mean number of listed members per relationship type (*SD*)	% of participants that listed the relationship type (*n*)	Mean number of listed members per relationship type (*SD*)
Partner	13.0 (18)	1.00 (0.00)	13.0 (18)	1.00 (0.00)
Parent	94.9 (131)	1.64 (0.50)	90.6 (125)	1.55 (0.50)
Child	2.2 (3)	1.00 (0.00)	2.2 (3)	1.00 (0.00)
Sibling	88.4 (122)	1.80 (1.17)	71.7 (99)	1.56 (0.82)
Extended family	79.7 (110)	5.76 (5.30)	55.1 (76)	4.25 (4.22)
In-law	40.6 (56)	1.68 (1.15)	29.7 (41)	1.49 (0.68)
Step-family	26.8 (37)	1.78 (1.55)	15.9 (22)	1.73 (1.72)
Foster family	5.1 (7)	7.00 (5.77)	5.1 (7)	2.00 (0.82)
Friends	13.8 (19)	1.53 (1.02)	10.9 (15)	1.27 (0.46)
Professionals	5.1 (7)	2.00 (1.53)	5.1 (7)	1.29 (0.49)
Volunteers	2.9 (4)	2.75 (3.50)	2.9 (4)	1.25 (0.50)
Other	10.1 (14)	1.79 (0.89)	7.2 (10)	1.50 (0.85)

Six out of the 131 participants who listed parents in their full family network, did not include any parent in their significant network. The small decline in mean number of listed parents (from 1.64 to 1.55) shows that most participants considered all parents as significant. With regard to siblings, both the number of participants that listed siblings as well as the mean number of listed siblings are lower compared to full family networks. This was also the case for extended family, step-family, and family in-laws.

All participants who included foster family, professionals, and volunteers in their full family network, also included foster family members in their significant network, though the mean number of members that were listed was lower. When it comes to friends and other relationships such as colleagues or neighbors, both the number of participants that cited the term and the mean number of significant friends and other members decreased. Even though based on small numbers, these findings indicate that professionals, volunteers, friends and other members who were regarded as part of their family, were not always considered to be "significant" family members.

Receiving and Giving Emotional Support

This subsection involves the subset of family members who are perceived by participants as providing them with emotional support (in-neighborhood; Hanneman & Riddle, 2005), or depending on them for support (out-neighborhood; Hanneman & Riddle, 2005). Participants reported feeling supported by a mean of 2.34 family members (*SD* = 1.60, range: 0 – 7). Of the participants, 7.2% (*n* = 10) indicated that they did not feel (emotionally) supported by anyone in their family. The most frequent numbers were that participants felt supported by two family members (30.4%) or had one supportive person in their family network (26.8%). Participants reported being a supportive person for a mean of 2.37 family members (*SD* = 3.54, range: 0 – 26). Thirty-six percent of participants (*n* = 49) did not consider themselves as a supportive person for anyone in the family, which was the most prevalent answer among participants. When a participant did see themselves as supportive to other family members, this was most frequently related to one other person (20.3%). Of the ten individuals who did not believe they received support from anyone in the network, six did not think that they provided support to anyone in their family, meaning that those six had no supportive connections with any family members.

Table 3 (left columns) presents the nature of the emotional support relationships (i.e., number of participants that listed the relationship(s) and total number of relationships). Parents were reported to be the main support provider and participants had the most supportive relationships (all directions) with parents. This was followed by extended family and siblings. However, only about one-third of participants reported these supportive relationships with extended family, meaning that this sub-group of

Table 3. Number of Relationships and Direction of Relationships per Nature of the Relationship

Nature of relationship to participant	Number of participants that listed the relationship type	Total number of relationships listed by participants	Direction of relationships: % of relationships with only received support (*n*)	% of relationships with only given support (*n*)	% of reciprocal relationships (*n*)
All relationships (total)	132	494	34.4 (170)	35.0 (173)	30.6 (151)
Partner	17	17	0.0 (0)	29.4 (5)	70.6 (12)
Parent	110	151	53.6 (81)	9.9 (15)	36.4 (55)
Child	3	3	0.0 (0)	100.0 (3)	0.0 (0)
Sibling	70	91	31.9 (29)	36.3 (33)	31.9 (29)
Extended family	45	128	17.9 (23)	69.5 (89)	12.5 (16)
In-law	19	29	31.0 (9)	37.9 (11)	31.0 (9)
Step-family	14	17	64.7 (11)	17.6 (3)	17.6 (3)
Foster family	6	12	50.0 (6)	0.0 (0)	50.0 (6)
Friends	12	19	0.0 (0)	36.8 (7)	63.2 (12)
Professionals	6	11	45.5 (5)	9.0 (1)	45.5 (5)
Volunteers	2	2	50.0 (1)	50.0 (1)	0.0 (0)
Other	8	14	35.7 (5)	35.7 (5)	28.6 (4)

participants had, on average, relationships with quite a few (2.84) extended family members.

Reciprocity of Emotional Support

Even though the mean numbers of relationships with family members in which support is given or received were found to be nearly equal, this finding does not necessarily imply that participants' relationships were viewed as reciprocal. Table 3 (right columns) provides an overview of the direction of relationships per type of relationship, indicating whether the relationship includes only received support, only given support, or reciprocal support. Overall, 30.6% of participants' support relationships were reciprocal, and 34.4% of participant's relationships only consisted of received support with 35.0% of relationships only included given support.

Table 3 also shows that the percentages per direction of relationships varied by the type of the relationship. First, relationships with peers (i.e., partner relationships and friendships) had a relatively high (above average) reciprocity. In some cases (29.4%, *n* = 5), participants reported that they were only providing support to partners and friends, though they never experienced receiving support from them without giving support.

In contrast, relationships with extended family members show the lowest level of reciprocity and participants believed to predominantly provide support to their extended family such as nieces/nephews, aunts/uncles, cousins, and grandparents. Lastly, relationships with siblings in which support was given or received, were the most balanced.

Using the FNM-ID, participants not only estimated the relationships between themselves and their family members, but also the relationships among all their family members (e.g., mother – sister). This estimated reciprocity of relationships among all family members in the participants' family networks was found to be 35.1% on average (not in table), as opposed to one-sided relationships in which it is estimated that only one family member provides support (64.9%). Thus, participants perceived only slightly greater levels of reciprocity in the relationships among the remainder of their family network than they perceived between themselves and their family members.

Discussion

This study is the first to systemically examine how a relatively large group of individuals with mild intellectual disability, who lived apart from their natural family, describe their family network and how they perceive the emotional support relationships with their family members and the reciprocal nature of these relationships. In the current study, it was not predefined for participants what constitutes their family. As such, participants may have used not only broader, but also narrower definitions than more traditional definitions of the concept family.

The findings of the study show that individuals with mild intellectual disability describe a variety of family groups, including significant family members beyond the nuclear family, such as extended family, in-laws, step-family, and friends. According to participants, the nuclear family of origin, and especially parents, played a prominent role in their social capital. That is, in total, participants had the highest number of relationships with parents and their parents were seen as the main support provider, which is in line with the reports of family members' themselves in terms of more practical support (Sanderson et al., 2017). In addition, even though only about one-third of relationships with parents were considered reciprocal, individuals with mild intellectual disability may also see themselves as being supportive to their parents. In a few cases (10% of reported relationships with parents), participants thought that they were supportive of their parents even though they did not feel this was reciprocated.

Siblings were considered to be part of the nuclear family of a large group (about 90%) of participants. However, smaller groups of participants considered their siblings as significant to them (70%), or experienced a support connection with them; only half

of participants reported a support relationship with (a) sibling(s). The number of relationships with siblings in which support was given and received was found to be quite balanced, as participants reported a nearly equal amount of relationships with their siblings in which support is given, received or reciprocated. In addition, it occurred that participants fulfilled a supportive role to their nieces and nephews. Interestingly, Kramer et al. (2013) found that reciprocal relationships among siblings with and without intellectual disability consisted of people with intellectual disability enacting specific family roles, such as fulfilling a role as an aunt or uncle, in exchange for their siblings providing them with access to resources in the community. However, the current study also shows that half of participants did not report support relationships with siblings. This finding is important in terms of the sustainability of their family-based social capital, as the *life expectancy* of individuals with intellectual disability has increased (Dieckmann, Giovis, & Offergeld, 2015), and the life expectancy of individuals with a mild disability may equal the expectancy for the general population (Bittles et al., 2002). This means that parents may no longer fulfill a key support role for the duration of their child's whole life. Older parents are likely to have increasing health problems and lower energy levels to provide support to their child with intellectual disability (Grey, Griffith, Totsika, & Hastings, 2015), and parents will die before their offspring.

The finding that partners and/or children were seldom (13%) part of participants' family networks is also of importance (Widmer et al., 2008; Widmer et al., 2013). Individuals with mild intellectual disability may often be missing this potentially significant source of social capital (Soulsby & Bennett, 2015). Partners were significant to participants, and research has shown that many individuals with an intellectual disability have expressed a desire for an intimate relationship, as these relationships may meet their needs for support, companionship, love, and affection (Giesbers et al., 2019; Healy, McGuire, Evans, & Carley, 2009; Rushbrooke, Murray, & Townsend, 2014).

Social capital is about the reciprocal exchange of supports (Bullen & Onyx, 1999). By not only receiving, but also contributing support, it is possible to build continuing relationships and exchanges. On average, participants had an equal amount (both about 2.3) of relationships with family members in which support was given and/or received. This finding indicates that, as a group, individuals with mild intellectual disability may not have a sense that they receive more support from others than they give (Gouldner, 1973). However, only 30% of participants' relationships were reciprocal and they estimated the support relationships between themselves and their family members as slightly less reciprocal than they estimated the overall reciprocity in their family networks. Moreover, substantial differences within the group of participants existed. About one third of participants did not believe that they fulfilled a support role for anyone in their family network. Earlier research pointed to the fact that such an over-

benefited position may have a negative influence on self-worth and self-esteem (Forrester-Jones & Barnes, 2008; Liang et al., 2001).

The ratio of given, received or reciprocated support also varied by the type of family relationship. Even though based on small numbers, relationships with partners and friends are relatively often (about 70% and 65% respectively) based on mutual support, a finding that highlights the potential and significance of intimate relationships and other peer relationships for individuals with mild intellectual disability (Friedman & Rizzolo, 2018; Neuman & Reiter, 2017). In contrast, participants had relatively few (13%) reciprocal relationships with extended family members (i.e., aunts/uncles, cousins, grandparents, and nieces/nephews), which seemed to be related to the relatively high number (70%) of unidirectional relationships with given support. Therefore, extended family seemed to be an important group within the family network, where participants felt they contributed in terms of providing support, though only about one-third of participants included extended family in their (significant) family network.

Limitations and Implications for Future Research

The results of the present study need to be considered within the context of a number of limitations. First, only 42.4% of the selected individuals who met inclusion criteria participated in the study. Therefore, a risk of non-response bias exists that may have negatively affected the representativeness of the sample. No other data were available for the non-respondents. Therefore, it was not possible to quantify biases in the sample selection. Second, the findings concerned a specific group of individuals with mild intellectual disability; all lived apart from family and were frequently supported by staff from a service provider. Future research should address the perspective of individuals with mild intellectual disability in different kinds of support arrangements. Third, even though the current study gives a detailed and valuable insight into the family support experiences of individuals with mild intellectual disability, it did not include a comparison group of individuals without intellectual disability. As such, this study does not provide insight into how the characteristics of the (significant) family networks and the support experiences of people with a mild intellectual disability compare to the network characteristics and family support experiences of people in the general population. Future research should include a comparison group to assess explicitly how the presence of a mild intellectual disability may influence access to family resources such as (reciprocal) emotional support. Also, while earlier research pointed to the fact that an over-benefited position with more received than given support may have a negative influence on the self-worth and self-esteem of the individual (Forrester-Jones & Barnes, 2008; Liang et al., 2001), the current study was descriptive in nature and did not include such measures. It might be of interest for future studies to examine whether there are

associations between reciprocity and the balance between given and received support of the individual on the one hand and experiences of self-worth and self-esteem on the other. In addition, the current study included a one-time data collection. Therefore, it would be important in future research to administer the FNM-ID in a longitudinal design to explore the robustness of reported family network data over time. Last, this study included quantitative family network data of a relatively large group of participants. It might be of interest for future research to include an in-depth exploration of how a smaller group of people with mild intellectual disability defines family members as significant and how they feel emotionally supported by, and emotionally supportive for, the family members of their choosing.

Implications for Practice

The current study showed that adults with mild intellectual disability were mainly dependent on their parents for their family-based social capital, while siblings might be more at a distance. However, the involvement of siblings in the lives of people with intellectual disability may be of great importance. Even though siblings are often expected to fulfil a key role in future support (Greenberg, Mailick Seltzer, Orsmond, & Wyngaarden Krauss, 1999; Heller & Arnold, 2010), parents may be reluctant to plan for the future and to involve siblings in their planning (Heller & Kramer, 2009). Therefore, it is important to involve siblings in support and future planning early on, as current sibling relationships may influence their future support expectations. In previous research, siblings had higher support expectations if they currently had more contact with their siblings with a disability and provided them with more support (Heller & Kramer, 2009). Therefore, staff and service providers should be aware of the important role that siblings play in the lives of their brother or sister with a disability, and their need to be involved in current and future support. In order to foster positive relationships, staff should also focus on the support that people with intellectual disability may be able to offer their siblings. As already stated, reciprocity helps to ensure continuing relationships and exchanges. Therefore, to build social capital in sibling relationships, it is important for staff to encourage reciprocity (Kramer et al., 2013; Smith, Greenberg, & Mailick Seltzer, 2007).

Moreover, while showing potential in reciprocal support provision, partners were seldom included in the family networks. Intimate relationships may contribute to the quality of life and sense of self-worth of people with mild intellectual disability (Neuman & Reiter, 2017; Rushbrooke et al., 2014). In addition, the absence of an intimate relationship has been shown to leave some individuals feeling unfulfilled and unable to achieve the ordinary future they want, settling down, getting married and having a family (Neuman & Reiter, 2017; Rushbrooke et al., 2014). As such, extra staff training

with regard to this topic might be needed (Bates, Terry, & Popple, 2017). It is important for support staff and family members to recognize the value of intimate relationships for people with intellectual disability, and to support them in forging and maintaining these relationships instead of being overprotective and controlling which could have a negative impact (Bates et al., 2017; Healy et al., 2009).

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CHAPTER 5

5

Perceptions of people with mild intellectual disability and their family members about family-based social capital

This chapter has been submitted for publication as:
Giesbers, S. A. H., Hendriks, A. H. C., Hastings, R. P., Jahoda, A., Tournier, T., & Embregts, P. J. C. M. (Submitted). Perceptions of people with mild intellectual disability and their family members about family-based social capital.

Abstract

Background

Families play an important role in the lives of people with intellectual disability as they do for everyone. Individual family members may hold different views about their family relationships. We used a social capital theoretical perspective to examine (1) how perceptions of people with mild intellectual disability about their family support networks compare to those of their family members, and (2) what factors are associated with any diverging perceptions.

Method

Participants with mild intellectual disability (n = 111) and their family members (n = 111) were interviewed individually using the Family Network Method – Intellectual Disability (FNM-ID). The FNM-ID examines how people define their family group, and how they perceive existing supportive relationships within this group.

Results

Participants with mild intellectual disability perceived that they had somewhat denser family networks (i.e., bonding social capital) than family members perceived them to have, and were more likely to report bridging social capital. They reported more relationships that involved them providing support to family members. This difference in estimation was greater when the participant with mild intellectual disability displayed higher levels of externalizing behaviour problems. They also perceived more reciprocity in their relationships with family. No differences were found in the estimated numbers of significant family members and relationships in which support was received.

Discussion

Participants with mild intellectual disability and their family members have different perceptions on several aspects of the family support network. Family, professionals and services should seek the views of people with intellectual disability and their family members when carrying out assessments or organizing supports.

The informal supportive networks of people with mild intellectual disability, which to a great extent are shaped by family members (Van Asselt-Goverts, Embregts, & Hendriks, 2013), have become increasingly important in a time of austerity and cuts to services. Accordingly, people with mild intellectual disability have become more reliant on their families for their support (e.g., Malli, Sams, Forrester-Jones, Murphy, & Henwood, 2018) and, as such, families may play an important role in facilitating social participation and inclusion (Simplican, Leader, Kosciulek, & Leahy, 2015).

Several studies have shown that social capital is a useful theoretical framework to examine support in the family relationships of people with mild intellectual disability, including their own perceptions (e.g., Giesbers et al., 2019; Kramer, Hall, & Heller, 2013; Widmer, Kempf, Sapin, & Galli-Carminati, 2013). Social capital centres on the mutual exchange of supports or resources between network members (Bullen & Onyx 1999). Within a social capital theoretical framework, supportive family relationships (i.e., family-based social capital, Furstenberg & Kaplan, 2004) are expected to promote physical and mental health, and well-being (e.g., McPherson et al., 2014; Umberson & Montez, 2010).

When examining support in families of people with mild intellectual disability from a social capital theoretical perspective, people with mild intellectual disability reported fewer family relationships with given and received support than people without disability (Widmer et al., 2008). These findings imply that their family-based social capital is lower on average. However, people with mild intellectual disability may experience different types of family arrangements with different levels of social capital (e.g., family relationships and social networks experienced by people with mild intellectual disability are different for those living with their family and those in community-based support settings (Widmer et al., 2013)).

Previous research has included the perceptions of people with mild intellectual disability about their family support experiences. To characterize individuals' perceptions of social networks, Krackhardt (1987) conceptualized social networks as cognitive structures, based on the assumption that "perceptions are real in their consequences, even if they do not map one-to-one onto observed behaviors" (p. 128). Even though family data derived from people with mild intellectual disability themselves is of great value, a perspective from a single informant within the family may be the view only of that individual family member. Several studies have shown that perceptions about the family are often not shared, and that family members experience the same events in different ways (e.g., Henggeler, Borduin, & Mann, 1987; Paulson & Sputa, 1996).

As Barnes and Olson (1985) noted, it may be advantageous to examine the extent that informants differ in their views of family relations, as the description of these differences may advance our understanding about the nature of family functioning. Widmer, Kempf-Constantin, and Galli-Carminati (2010) found that, compared with a

non-clinical sample, 17 people with mild intellectual disability and psychiatric disorders perceived less support within their families. Their family members held the same view about a lack of family support. However, there were differences in the perceptions of people with mild intellectual disability and their family members, with regards to the size and density of the family network of the person with mild intellectual disability. Widmer et al.'s study (2010) focused on a relatively small, purposive sample of people with mild intellectual disability and psychiatric disorders residing in a psychiatric unit of a hospital. We recruited a much larger random sample of 111 people with mild intellectual disability (and a family member) with and without comorbid psychopathology, who received support within intellectual disability services. The aims of the study were: (1) to examine support in the family networks of people with mild intellectual disability, by assessing both their own perceptions, and the perceptions of their family members about the network of the person with mild intellectual disability, and (2) to examine what factors are associated with any divergence in perceptions of the person with mild intellectual disability and their family member. Potential correlates of divergence in perceptions were: sex (e.g., Vigil, 2007), type of support/living setting (Kozma, Mansell, & Beadle-Brown, 2009), and the number of years living apart from family (as all lived apart from family; Widmer et al., 2013), well-being (e.g., Umberson & Montez, 2010), and internalizing and externalising behaviour problems (e.g., McPherson et al., 2014).

Method

Participants

Participants were people with mild intellectual disability (IQ 50-70; *n* = 111) and their family members (*n* = 111). Key support workers were included in the study as proxy informants on the behavioural and emotional problems of the participants with mild intellectual disability.

The age of participants with mild intellectual disability ranged from 18 to 40 years (*M* = 28.4 years, *SD* = 6.08), and 62 (55.9%) were male. Seventeen (15.3%) participants lived in residential facilities, whereas the vast majority of 94 participants (84.7%) lived in community-based settings. On average, participants had lived apart from their family for 10.6 years (*SD* = 6.19, range 1 – 31 years). A majority (*n* = 69, 62.2%) lived together with other people with intellectual disability, 35 (31.5%) lived individually, four (2.7%) lived together with a partner, and three (2.7%) had another form of living arrangement (e.g., together with their child). All but six participants with mild intellectual disability had a Dutch cultural background (94.6%) and 50 (45.5%) had at least one diagnosis in addition to their mild intellectual disability. Participants were diagnosed with autism (*n* = 26), a disorder of impulse- or aggression regulation (*n* = 9), a genetic syndrome (*n*

= 7), attention deficit hyperactivity disorder (*n* = 5), personality disorder (*n* = 6), attachment disorder (*n* = 4), post-traumatic stress disorder (*n* = 2), or other (*n* = 5; e.g., psychotic disorder or tic disorder). Fifteen (13.5%) had sensory impairments and 28 (25.2%) participants had a physical impairment (e.g., cerebral palsy, respiratory problems, or motor impairment) in addition to mild intellectual disability.

Family members had a mean age of 55.7 years (*SD* = 11.65, range 26 – 79), 74 (66.7%) were female, and all but seven had a Dutch cultural background (93.7%). The majority of family members were parents of the participants: 55 mothers (49.5%) and 25 fathers (22.5%). Fifteen (13.5%) were siblings, five (4.5%) were extended family (e.g., aunt, grandparents), five (4.5%) were foster parents, three (2.7%) were step-parents, one (0.9%) was a partner, and two (1.8%) were friends.

The mean age of the key workers was 41.2 years (*SD* = 10.66, range 25 – 63 years), and 90 (81.1%) were female. They had been working in the field of intellectual disability for 18.2 years on average (*SD* = 10.43, range 3 – 45 years). Most staff (94.5%) had received specific training in the field of social work or health care; 67 (60.9%) obtained an intermediate vocational training and 37 (33.6%) higher education.

Measures

Family networks

Participants with mild intellectual disability and family members were interviewed individually using the Family Network Method – Intellectual Disability (FNM-ID; Giesbers et al., 2019). The FNM-ID is designed to map the family network and to identify significant family members, as well as family members who provide emotional support. Consistent with the FNM-ID procedure described in Giesbers et al. (2019), participants with mild intellectual disability were asked about their perception of their family support network. Family members were interviewed about their perception of their relative's support network.

The FNM-ID has four main steps. First, participants are instructed to map the family network. The term 'family' is not defined by the researcher; participants are told to use their own definition of 'family' and define who they consider to be their (or their relative's) family. Second, participants are invited to define significant family members (according to their own definition) from those listed in the first step. The third step concerns questions about emotional support provision. Participants not only estimate their own relationships with their family members (or in case of family members: The relationships between their relative and their family members), but also the relationships existing among all family members (e.g., "When grandpa is feeling out-of-sorts, who is there for him?"). Key demographic characteristics of all the listed family members (e.g., gender, age, place of residence) are also collected.

Subjective well-being

A Dutch version of the Personal Wellbeing Index-Intellectual Disability (PWI-ID; Cummins & Lau, 2005) was used with the participants with mild intellectual disability. The original PWI-ID was translated using a forward-backward translation procedure (Dewolf, Koller, Velikova, Johnson, Scott, & Bottomley, 2009) by four translators who reached consensus on the items, and was piloted with individuals with mild intellectual disability. The PWI-ID contains seven satisfaction items rated on a five-point Likert scale, each corresponding to a quality of life domain and one question about "satisfaction with life as a whole". McGillivray, Lau, Cummins, and Davey (2009) reported a Cronbach's alpha of .76 and the domains form a single stable factor that predicts over 50% of the variance in "satisfaction with life as a whole". Within the current study, the sum score of the seven quality of life domains was used.

Cognitive ability

Two subtests (i.e., Vocabulary and Matrix Reasoning) of the Dutch Wechsler Adult Intelligence Scale (WAIS-IV-NL; Wechsler, 2012) were administered to participants with mild intellectual disability only. These two WAIS-IV-NL subtests correspond with the two-subtest form of the Wechsler Abbreviated Scale of Intelligence (WASI-II; Wechsler, 2011). As no Dutch WASI-II is available, an estimation of IQ scores was made based on the subtest standard scores of the two corresponding WAIS-IV subtests. When both WAIS-IV-NL standard scores were indicative of a level of cognitive ability above or below the mild intellectual disability range (taking the standard error into account), a participant was considered to not have mild intellectual disability. An additional check on the inclusion criterion of having mild intellectual disability (IQ 50-70) was included in the study because clinical file scores were often outdated, missing, or obtained with unidentified IQ tests.

Behavioural and emotional problems

The Dutch Adult Behaviour Check List (ABCL; Achenbach & Rescorla, 2003) was completed by the key support workers. The ABCL consists of 118 items (using a 3-point scale) and examines a broad range of behavioural and emotional problems. We used the scales concerning internalizing behaviour (i.e., anxious/depressive problems, somatic complaints, and withdrawn behaviour) and externalizing behaviour (aggressive behaviour, rule-breaking behaviour, and intrusive behaviour). Psychometric data suggest that this instrument can be used with people with mild intellectual disability (Cronbach's alpha ranged from .69 to .95 (M = .84), inter-rater reliability ranged from .57 to .76 (mean ICC = .68); Tenneij & Koot, 2007).

Procedure

Ethical approval was obtained from the Ethical Review Board of Tilburg University (EC-2015.46). Participants with mild intellectual disability were recruited from five intellectual disability services in the Southern Netherlands. Inclusion criteria were: 1) mild intellectual disability (IQ 50-70) initially according to file records (later confirmed), 2) aged 18-40 years, and 3) receiving professional support at least once a week for a minimum of six months. Living with their birth family was an exclusion criterion for participants, as family support is found to be associated with living situation (Widmer et al., 2013). Participants were randomly selected from each service provider using a stratified sampling procedure (i.e., stratified by service provider). Service providers were asked to determine the total number of their service users who met the inclusion criteria of the study. From each service provider, 10% of their service users who met inclusion criteria participated in the study to reach the target number of about 150 participants (see Figure 1 for an overview of the sampling procedure). The number of participants with mild intellectual disability per service provider varied from 14 to 50.

Participants with mild intellectual disability were always approached in consultation with their key worker. The researcher contacted the key workers by telephone and sent an information letter to the key workers, and they were asked to discuss the letter with the selected potential participants with mild intellectual disability. The researchers approached the key workers of 354 people with mild intellectual disability who met inclusion criteria, and 150 participated (42.4%). The main reason for non-response was that the invited person did not wish to participate (n = 117, 57.4%). Other reasons for non-response were that, before inviting the service user, psychologists and/or support staff advised against participation (e.g., the expected burden was too high; n = 59, 28.9%), or relatives/guardians did not agree with inviting the person (n = 21, 10.3%). Some key workers were unable to facilitate participation of service users due to high workload and time constraints (n = 7, 3.4%).

For the service users who were willing to participate in the study, an appointment was made at their home or another location they preferred. Participants with mild intellectual disability were visited individually by a researcher (the first or fifth author, or a research assistant) for 45--60 mins per visit. In a few cases (6.7%), not all measures could be completed during one visit (participants showed signs of distractibility or fatigue, or they themselves indicated that they would like to complete the measures at another time), and a second visit was needed. All visits started with smalltalk to put the participant at ease. To ensure that participants with mild intellectual disability were able to give their informed consent, a standard consent procedure was followed (Arscott, Dagnan, & Stenfert Kroese, 1998). After consent was obtained, the WAIS-IV-NL subtests were administered. Second, demographic information was gathered using a computer administered set of questions (after the visits, with the consent of participants, the

researcher contacted the psychologist or key worker for each participant with mild intellectual disability to ask for possible additional, official diagnoses). The researcher read each item out loud and the participant replied verbally. Either the researcher or the participant digitally recorded the response. Third, the PWI-ID was computer-administered to participants, using the same procedure. The main task was completed last and involved interviewing the participants about their family network using the FNM-ID, following the prescribed interview protocol (Giesbers et al., 2019), and all FNM-ID interviews were audio recorded. At the end of the FNM-ID interview, participants were asked to select one of their family members that could best be questioned about their family support experiences and were asked permission to approach that family member to participate in the study. Eleven participants did not gave their permission to invite a family member for participation.

Family members who could be invited to participate were first asked for permission (by their relative or the key worker) to share their contact details with the researchers, after which an information letter was sent and the researchers contacted them by telephone to explain the study. If a family member was willing to participate, an appointment was scheduled at their home or on the service provider's premises. Of the 150 family members that could potentially participate in the study, 139 were invited to participate, and 120 participated (80.0%). Reasons for non-response included protracted illness of a family member, the expected burden of participation was perceived as too high, or family members had no interest in the study. Family members were visited individually 45--60 mins. After informed consent was obtained, family members were questioned about their perceptions of their relative's network. Key demographic information about the family member was also collected.

For each participant with mild intellectual disability, the key support worker (as identified by the support provider) who had supported the individual for at least 6 months was invited by the research team (with the consent of the participant with mild intellectual disability) to complete the ABCL as a proxy informant. Proxy-report instead of self-report was used to reduce the demand placed on participants with mild intellectual disability. After informed consent was given, the ABCL was computer-administrated.

The current analysis only included data from dyads of participants with mild intellectual disability and their family members. Data from an additional nine participants were excluded from the study because both WAIS-IV-NL standard scores were indicative of a level of cognitive ability above or below the mild intellectual disability range. In addition, data from the FNM-ID for one participant were excluded from the study; scores on all but one measures were found to be extreme outliers (3SDs or more above the mean). Therefore, 111 complete dyads of people with mild intellectual disability and family members were included in the current analysis (see Figure 1).

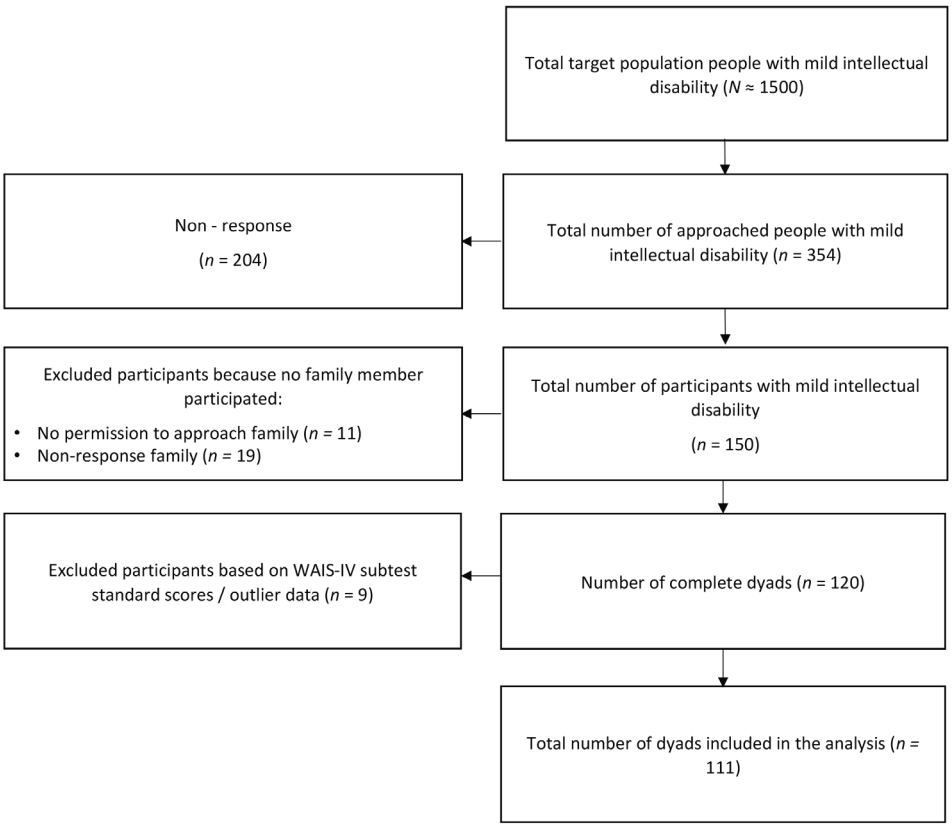

Figure 1. Overview of the sampling procedure

Data Analysis

Family network data were analyzed using UCINET (Version 6.623; Borgatti, Everett, & Freeman, 2002). First, several social network measures, of interest from a social capital theoretical perspective, were computed (see Table 1). In a second step, Paired samples *t*-tests were conducted to examine differences in the characteristics of the family networks perceived by the participants with mild intellectual disability and their family members. A standardized mean difference effect size for paired designs, *d* was calculated using $t[2(1-r)/n]^{1/2}$ (Dunlap, Cortina, Vaslow, & Burke, 1996). A conservative 0.80 was used to estimate *r*.

Third, as this study focused on factors that may account for divergence in perceptions of people with mild intellectual disability and their family on key social capital measures, dyad difference scores were calculated for the measures that revealed significant differences at the second step (i.e., network density, dyad reciprocity, and out-degree).

Individual scores within a dyad are nested data involving two levels (individual – dyad) (Gonzalez & Griffin, 2012). However, when using difference scores only the dyadic level is included in the analysis.

Next, factors that may account for different perceptions between people with mild intellectual disability and their family on divergent network measures were examined using multiple regression analyses with the dyad's difference score on that network measure as the dependent variable. By using a residual change approach (Castro-Schilo & Grimm, 2018), it is not assumed that all dyads have the same mean. Therefore, the mean score of the dyad on the dependent variable was included as a predictor, to correct for different dyad mean scores. The other predictors for each regression model were: the sex of the participant with mild intellectual disability, the number of years the participant with mild intellectual disability had lived apart from family, the subjective well-being of the participant with mild intellectual disability, whether the participant with mild intellectual disability resided in a residential vs community living setting, and the level of internalizing and externalizing behavioural and emotional problems.

During the initial inspection of the computed social network measures, two cases with extreme difference scores (3SDs or more above or below the mean) – one on the size of the significant network and one case with extreme difference scores on out-degree - were excluded from the analyses. In addition, scores on the individual network measure "betweenness centrality" were found to strongly deviate from a normal distribution, as difference scores were centered around zero (Skewness: 6.86, Kurtosis: 53.54). This finding was related to the fact that 70 (63.1%) participants with mild intellectual disability and 93 (83.8%) family members estimated a betweenness centrality score of zero, resulting in high levels of agreement (difference score of zero). Therefore, the estimates of "betweenness centrality" were dichotomized into zero – not zero, and a McNemar's test for paired data was performed to test differences in the estimation of a zero – non zero "betweenness centrality" between groups. In a second step, dyad difference scores on "betweenness centrality" were dichotomized into agreement – non-agreement, and factors that may account for (non-) agreement were tested in a logistic regression analysis.

Results

Group Differences in Network Perception

Network Measures

Paired samples *t*-tests (see Table 2), and a McNemar's test were conducted to examine differences in the characteristics of the family networks perceived by the participants with mild intellectual disability and their family members.

Table 1. Overview of the Computed Social Network Measures

Network Measures – full network	Size	Number of listed family members
Network measures – significant network	Size	Number of significant family members
	Density	The number of relationships between network members compared to the maximum possible numbers of relationships that could theoretically exist between all family members
	Dyad Reciprocity – all relationships	The number of dyads in the network with reciprocal relationships, divided by the total number of adjacent dyads in the network
Individual family network measures for people with MID	In-degree	Number of relationships in which the person with mild intellectual disability receives support
	Out-degree	Number of relationships in which the person with mild intellectual disability provides support
	Betweenness centrality	Quantifies the number of times the person with mild intellectual disability acts as a bridge along the shortest path between two other network members
	Dyad Reciprocity – relationships of participant only	Number of dyads (in which the person with mild intellectual disability is an actor) with reciprocal relationships, divided by the total number of adjacent dyads (in which the person with mild intellectual disability is an actor)

For network measures (concerning the network as a whole), participants with mild intellectual disability perceived their significant family networks to be more dense than did family members, $t(110) = 2.12$, $p = .037$, with a small effect size. The difference in the estimation of dyad reciprocity was not statistically significant, $t(110) = 1.81$, $p = .073$.

Individual network measures

Participants with mild intellectual disability perceived that they had more relationships with network members in which they gave support (i.e., out-degree), than family members perceived, $t(109) = 4.41$, $p < .001$, with a small effect. Also, they experienced their relationships with network members as more reciprocal than did family members, $t(110) = 3.10$, $p = .002$, also with a small effect size. Finally, McNemar's test (not in Table 2) showed that participants with mild intellectual disability were significantly more likely (OR 1.10) to report a "Betweenness centrality" that was non-zero, $p = .001$.

Correlates of Divergence

Multiple regression models for network density, $F(7,103) = 1.67$, $p = 0.126$, $R^2 = .10$, and dyadic reciprocity $F(7,103) = 1.69$, $p = .120$, $R^2 = .10$ were not statistically significant overall and none of the individual predictors were significant independent predictors (Table 3). For out-degree the overall model was significant, $F(7,102) = 5.95$, $p < 0.001$, $R^2 = .29$.

Table 2. Mean Numbers of the Network Measures for Participants, *t, df, p, d*

	Variable	Mean(*SD*)		*t*	*df*	*p*	*d*
		Individuals with MID	Family members				
Full network	Size	11.40 (6.61)	12.36 (7.63)	-1.34	110	0.184	-0.080
Significant network	Size	7.14 (4.52)	7.10 (3.86)	0.08	108	0.935	0.005
	Density	0.36 (0.24)	0.30 (0.20)	2.12	110	0.037	0.127
	Dyad Reciprocity – all relationships	0.38 (0.30)	0.31 (0.25)	1.81	110	0.073	0.109
Measures for individuals with MID	In-degree	2.37 (1.58)	2.23 (1.45)	0.72	110	0.471	0.043
	Out-degree	2.14 (2.74)	0.85 (1.72)	4.41	109	< 0.001	0.266
	Dyad Reciprocity – relationships of participant only	0.28 (0.33)	0.15 (0.28)	3.10	110	0.002	0.186

Table 3. Summary of Multiple Regression Analyses for Variables Predicting Dyad's Difference Scores

	Density (*n* = 111)			Out-degree (*n* = 110)			Dyad Reciprocity (*n* = 111)		
Variable	***B(SE)***	***t***	***p***	***B(SE)***	***t***	***p***	***B(SE)***	***t***	***p***
Sex	.073(.060)	1.22	.227	.648(.542)	1.20	.234	.065(.088)	0.74	.459
Years of living apart from family	.004(.005)	0.76	.447	.025(.043)	0.59	.558	.011(.007)	1.66	.101
Well-being	.015(.009)	1.78	.079	.025(.076)	0.33	.743	.007(.013)	0.55	.581
Living setting	-.135(.081)	-1.66	.100	.382(.733)	0.52	.604	.005(.118)	0.04	.970
Internalising behaviour	-.001(.004)	-0.19	.850	-.025(.035)	-0.73	.466	.004(.006)	0.66	.508
Externalising behaviour	.003(.003)	1.10	.276	.080(.028)	2.90	.005	.005(.004)	1.07	.287
Dyadic Mean Score	.281(.182)	1.55	.125	.783(.158)	4.95	< .001	.293(.200)	1.47	.145

Note. Constant = -0.57 (Density), -2.30 (Out-degree), -0.44 (Dyad Reciprocity)

Externalizing behaviour problems and the dyad's mean score on out-degree added independently to the prediction. A higher score on externalizing behaviour and a higher mean score of the dyad on out-degree predicted larger differences in out-degree estimations.

The logistic regression model for betweenness centrality was not statistically significant, $\chi^2(6) = 11.70$, p = .069 (Table 4). The model explained 13.4% (Nagelkerke R2) of the variance in agreement on betweenness centrality. While the model was not statistically significant overall, women with mild intellectual disability were 3.01 times more likely than men with mild intellectual disability to disagree with family members about whether betweenness centrality is zero or non-zero (p = .013).

Table 4. Summary of Logistic Regression Analysis for Variables Predicting Dyad's (non-)Agreement on Betweenness Centrality of the Participant with Mild Intellectual Disability (*n* =111)

Variable	*B(SE)*	Wald χ^2	*p*	OR	95% CI OR
Sex	1.102(.444)	6.17	.013	3.01	[1.26-7.18]
Years of living apart from family	- .036(.034)	1.10	.294	0.97	[0.90-1.03]
Well-being	.119(.065)	3.35	.067	1.13	[0.99-1.28]
Living setting	.103(.584)	0.03	.860	1.11	[0.35-3.48]
Internalising behaviour	- .029(.027)	1.16	.282	0.97	[0.92-1.02]
Externalising behaviour	.036(.022)	2.63	.105	1.04	[0.99-1.08]

Note. Constant = -3.82

Discussion

The findings suggest differences between participants with mild intellectual disability and their family members about their perceptions of the family support network of the person with mild intellectual disability. Contrary to the findings of Widmer et al. (2010), participants with mild intellectual disability in this study perceived their family network to be more dense than did their family members. Participants with mild intellectual disability perceived more relationships among their network members, meaning that they experienced a somewhat higher level of bonding social capital. Bonding social capital is often advantageous (Coleman, 1988), as it provides the norms and trust that facilitates collaborative action, and can fulfil a valuable social function by providing a source of collective support. However, it has also been suggested that bonding social capital can be a source of strain, and a barrier to experiencing individual autonomy, potentially leading to conflicts (Ferlander, 2007).

Participants with mild intellectual disability were also more likely to estimate a betweenness centrality different to zero when compared to their family members. People with mild intellectual disability were thus more likely to report experiences of bridging social capital. Bridging social capital may enhance feelings of competence, control, and autonomy of people with mild intellectual disability within their families (Woolcock, 1998). However, participants with mild intellectual disability and family members most frequently reported no bridging social capital at all (63.1% and 83.8% respectively).

Furthermore, participants with mild intellectual disability reported more relationships that involved them supporting the family member, than did family members. Participants with mild intellectual disability were also more likely to report reciprocal relationships with family members. Reciprocity is an essential aspect of social capital (Bullen & Onyx 1999). Being able to support others may enhance the individual's self-worth and self-

esteem (e.g., Liang, Krause, & Bennett, 2001). People with intellectual disability in previous research stressed that reciprocal relationships are of great importance to make them feel useful, and to challenge feelings of dependence (Milner & Kelly, 2009). However, their relationships are often not based on reciprocity (Giesbers et al., 2019), and the current findings show that the participants' sense of reciprocity within family relationships was not always recognized by their family members.

Reciprocity helps to ensure continuing relationships and exchanges (Bullen & Onyx, 1999). Therefore, when aiming to involve and strengthen family support networks, it is important for services to consider the support that people with mild intellectual disability may be able to offer to their family members. Though beneficence may be responsible for initiating caregiving actions (Gouldner, 1973), not all family members are able to cope with and maintain a caregiving role, and reciprocity in care and support may be a mechanism that contributes to sustained support from family members. Several studies have shown the positive effects of reciprocity on caregiver well-being (Reid, Moss, & Hyman, 2005; Heller, Miller, & Factor, 1997). Therefore, it may be important for services to support people with mild intellectual disaiblity to actively engage in family exchanges. The culture within disability services, and especially in residential settings, seems often to be one of care, with staff prioritising care tasks over tasks to promote social inclusion (McConkey & Collins, 2010). Staff could be more aware of their role in facilitating meaningful contact with significant others. They could support people's continued involvement and engagement with family members and other significant others in simple ways by, for example, making family and other network members feel welcome and encourage people with mild intellectual disability to invite them to visit (Francis, Blue-Banning, Haines, Turnbull, & Gross, 2016), help people write messages, send cards or buy presents to mark key occasions (Kuis, Hermsen, Van Heijst, Timmermann, & Embregts, 2018), or by supporting them to take a family member (e.g., a niece or a nephew) out for a trip (Kramer et al., 2013). Additionally, the current findings show that when encouraging (reciprocal) family support it is important for services to include the perceptions of people with mild intellectual disability themselves, but also the perceptions of their significant others, as perceptions about family relationships from individual members may not necessarily converge. It is important for staff to initiate a dialogue with both people with mild intellectual disability and their significant family members, and encourage them to share their individual experiences, needs, and wishes.

Perceptions of participants with mild intellectual disability and family members did not diverge on all aspects of family relationships. Contrary to Widmer et al. (2010), no significant differences were found in the perceptions of the number of significant family members that make up the network and the number of family relationships in which support is provided to the person with mild intellectual disability. Participants with mild

intellectual disability did not perceive different levels of supportive resources from the family. While family members do not always recognize the supportive behaviours of people with mild intellectual disability (see earlier), they perceived similar levels of supportive behaviours from the family to the person with mild intellectual disability.

An examination of factors that may account for divergence in perceptions between people with mild intellectual disability and their family members found associations between divergence on out-degree estimates and externalizing behaviour. Several explanations for this finding may exist. First, inflated self-perceptions might be at play: Children with externalizing behaviour problems tend to overestimate their academic and behavioural functioning, as well as inflate their status in, and quality of, social relationships with both peers and family members (Barry, 2011). Another explanation might be that people who increasingly lack the family's recognition of their supportive behaviours, may develop lower levels of self-esteem (Liang, Krause, & Bennett, 2001), which in turn may lead to increased levels of externalizing behaviours (Donnellan, Trzesniewski, Robins, Moffitt, & Caspi, 2005). Finally, family members of people with intellectual disability who display externalizing behaviours experience increased stress and emotional difficulties (Dreyfus & Dowse, 2018). For these family members, building rewarding or reciprocal relationships, in which their relative's supportive behaviours are recognized, may be challenging or the experienced difficulties may affect their perceptions of their relative's place in the family. We also found that women were significantly more likely than men to disagree with family members on their bridging social capital. This might be linked to gender biases: Women's bridging roles in friendship networks were significantly under-recognised by other network members (Brands & Kilduff, 2014).

A number of sampling and methodological issues are important to discuss as they relate to the generalisability of the current findings. First, there is a risk of non-response bias. Only 42.4% of the invited people with mild intellectual disability accepted the invitation to participate. As no other data were available for the non-respondents, it was not possible to quantify biases in the sample selection. Additionally, 30 of the eligible 150 family members did not participate in the current study and only the data of people with mild intellectual disability with a participating family member were included (thus, findings should be generalized with caution). Third, the findings concerned a specific group of people with mild intellectual disability; all lived apart from family and were frequently supported by staff from a service provider. Future research should address the perceptions of individuals with mild intellectual disability who live, for example, at home with and without professional support. Fourth, this study was based on the perceptions of people with mild intellectual disability and one of their family members only. Though this study makes a valuable contribution to our understanding about relationships in families of people with mild intellectual disability,

each individual family member may experience the same family relationships in different ways (e.g., Henggeler, Borduin, & Mann, 1987). Therefore, future studies could use a multi-informant network research designs in which all members of the family are interviewed on all relationships within the family. Finally, when exploring factors that are associated with divergence in perceptions between people with mild intellectual disability and family members, the current study showed associations with externalizing behaviour and the sex of the person with mild intellectual disability only. Future research could explore other factors such as the closeness and frequency of the contact between the person with mild intellectual disability and the family member, the level of intellectual disability, and adaptive functioning (Schmidt et al., 2010). Despite these limitations, the current study contributes to our understanding of relationships in the family networks of people with mild intellectual disability by demonstrating how their own perceptions compare to those of their family members.

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CHAPTER 6

6

Family-based social capital of emerging adults with and without mild intellectual disability

This chapter has been resubmitted for publication as:
Giesbers, S. A. H., Hendriks, A. H. C., Hastings, R. P., Jahoda, A., Tournier, T., & Embregts, P. J. C. M. (resubmitted). Family-based social capital of emerging adults with and without mild intellectual disability.

Abstract

Background

Family is recognised as an important context for the self-development of young adults in emerging adulthood, though very little research has addressed the perspective of young people with intellectual disability about their families by using self-report. This study examined how emerging adults with mild intellectual disability define their family support networks, compared with definitions of students without intellectual disability, within a social capital theoretical framework.

Method

Fifty-three participants with mild intellectual disability and 53 students without intellectual disability were interviewed individually using the Family Network Method – Intellectual Disability (FNM-ID). The FNM-ID explores how individuals define their family groups, and how they perceive existing supportive relationships within their families. Data were analysed quantitatively using social network analysis and further analysed to compare groups.

Results

Participants with mild intellectual disability reported fewer "significant" family members than students without intellectual disability. They were less likely to include peers (i.e., friends and partners) and siblings in their significant family networks, had fewer relationships with family members in which they received or gave support, had fewer reciprocal support relationships, and had a less central position in their family network.

Discussion

The family-based social capital of emerging adults with mild intellectual disability differed from that of students without intellectual disability. They may remain more dependent on their natural family for emotional support as their supportive networks have not necessarily made the transition to networks with emotionally close peer relationships.

The Convention on the Rights of Persons with Disabilities (CRPD; United Nations, 2006) aims for "full and effective participation and inclusion in society" (Art. 3) of people with disabilities. More specifically, the CRPD recognises the importance of individual autonomy and independence of people with disabilities, including the freedom to make their own decisions.

The period in life when individuals typically focus on their self-development and development of individual autonomy is known as emerging adulthood (Arnett, 2000). Emerging adulthood is conceptualised as a relatively new and distinct period in the life course of young individuals in the transition to adulthood (between 18 and 25 years of age). It is characterised by increased autonomy and identity exploration of work, love, and worldviews as well as gradually becoming self-sufficient (Arnett, 2000); that is, becoming a person who accepts responsibility for oneself and is able to make independent decisions (Arnett, 1998). From a relational autonomy perspective, self-development takes place within the social context in which individuals are embedded, in relationships with other people (Mackenzie & Stoljar, 2000; Walter & Friedman Ross, 2014).

Family is an important context for the self-development of individuals (Kagitcibasi, 2005). During emerging adulthood, most individuals' supportive networks transition from family-centred networks to networks that are more centred around peers, and the function of family relationships may change significantly (Aquilino, 2006; Conger & Little, 2010; Fraley & Davis, 1997; Tanner, 2006). In particular, parents and siblings become more peripheral, whereas romantic partners and friends have a more central place in daily life, with increased intimacy, emotional depth and communication about important personal matters (Collins & Van Dulmen, 2006). Ferguson and Ferguson (1996) refer to these changing family relationships as the familial adulthood, as differentiated from the personal and cultural adulthood. The familial meaning of adulthood involves gradually changing relationships between a person and his or her parents and family, resulting in increased independence and autonomy for the person and less involvement and responsibilities for parents.

Family clearly also plays a significant role in the lives of people with intellectual disability (Sanderson, Burke, Urbano, Arnold, & Hodapp, 2017; Van Asselt-Goverts, Embregts, & Hendriks, 2013). Research suggests that social networks of adults with mild intellectual disability mainly consist of family members, and include relatively few friends (Lippold & Burns, 2009; Rosen & Burchard, 1990; Van Asselt-Goverts et al., 2013). Also, the inclusion of romantic partners is rare (Widmer, Kempf, Sapin, & Galli-Carminati, 2013), and parents remain the main providers of informal support, not only for practical (Sanderson et al., 2017), but also emotional support (Giesbers et al., 2019). As such, for emerging adults with intellectual disability it may be difficult to attain adult roles within their family (Mill et al., 2009; Walmsley, 1996).

Despite the recognition of the significance of the family for people with intellectual disaiblity, very little research has addressed the perspective of people with intellectual disability about their families by using self-report. Also, the research literature requires a theoretical foundation and associated methodology to build an evidence base about how individuals with intellectual disability conceive of their family as well as the impact their family has on their lives. It is important to examine how people with intellectual disability themselves define their significant family group in emerging adulthood, compared to people without disabilities.

A potentially relevant theoretical perspective is that family could be considered as a significant source of social capital (Bourdieu, 1986; Furstenberg & Kaplan, 2004; Widmer, 2016). Social capital is about the mutual exchange of supports or resources between individuals (Bullen & Onyx, 1999). From a social capital perspective, positive and supportive family relationships that may go beyond the nuclear family (i.e., family-based social capital) are expected to have a variety of positive outcomes for the individual, such as promoting physical and mental health (Kawachi & Berkman, 2001; Kawachi, Kennedy, & Glass, 1999; McPherson et al., 2014; Riumallo-Herl, Kawachi, & Avendano, 2014). Widmer, Kempf-Constantin, Robert-Tissot, and Galli-Carminati (2008) examined the views of individuals with mild intellectual disability about their family from a social capital theoretical perspective. Widmer et al's findings suggest that family-based social capital is influenced by the presence of an intellectual disability. This held true for both types of social capital that are related to the family: bonding and bridging social capital (Coleman, 1988; Burt, 1995). Bonding social capital refers to dense networks in which all or most individuals are interconnected (Coleman, 1988). Dense networks enhance expectations, obligations, and trust among their members and support becomes collective. The second kind of social capital is bridging social capital, referring to the absence of relationships in a network that create relational holes in its structure (Burt, 1995). As a result, some individuals (i.e., brokers) are more central in a network and mediate the flow of resources among network members, and therefore influence others, leading to feelings of autonomy, competence, and control (Burt, 1995). Widmer et al. (2008) found that adults with mild intellectual disability had less dense networks than people without disability (i.e., bonding social capital). They also had a less central position in their network (i.e., bridging social capital), meaning that they may experience less autonomy, competence, or control within their families. This finding was even stronger for people with comorbid psychiatric disorders. However, this previous work relied on a small purposive sample and did not include specific measures of reciprocity, which is one of the main characteristics of social capital. Also, previous research has not used network methodology that has been adapted for people with intellectual disability.

We could find no studies from a social capital theoretical perspective with a specific

focus on the significant networks of individuals with mild intellectual disability in the important transition period of emerging adulthood, nor on reciprocity as a characteristic of mutual exchange of these family networks of individuals with mild intellectual disability. In addition, relatively few studies have used comparison groups of people without intellectual disability with which to evaluate the impact of disability on young people's experiences of family-based social capital. Therefore, the current study focusses on the way a group of randomly sampled emerging adults with mild intellectual disability who live apart from family define their significant family group and how they describe their family networks in terms of emotional support compared with students of the same sex and age who live apart from family, using family network methodology that has been adapted for people with mild intellectual disability within the theoretical framework of social capital (Giesbers et al., 2019).

Method

Participants

Participants were 53 individuals with mild intellectual disability (IQ 50-70) and 53 students without intellectual disability in post-secondary education. Participants with mild intellectual disability had a mean age of 22.0 years (*SD* = 2.38, range 18 - 25 years). Thirty-four (64.2%) were male and all but three (94.3%) had a Dutch cultural background. All participants with a mild intellectual disability lived apart from their family in housing with support from a service provider; a majority of 41 participants with disability (77.4%) lived in community based settings (i.e., group homes or (clustered) apartments located in the community), and 12 lived in residential, more segregated, facilities (i.e., sites where larger numbers of people with intellectual disability live together). Of the participants with mild intellectual disability, 32 (60.4%) lived together with other service users, 19 (35.8%) lived individually, one lived together with a partner, and one lived together with a brother (both 1.9%).

Students had a mean age of 21.6 (*SD* = 2.09, range 18 - 25 years) and thirty-two (60.4%) were male. All students had moved out the family home: A majority of 33 students lived together with (a) roommate(s) (62.3%), 13 lived together with a partner (24.5%), five lived individually (9.4%), one lived together with a friend, and one lived together with a brother (both 1.9%). Forty-seven students (88.7%) had a Dutch cultural backgrounds and students were studying on three levels: vocational training (*n* = 21, 39.6%), university of applied sciences (*n* = 20, 37.7%), and university (*n* = 12, 22.6 %). Vocational training focuses on the necessary knowledge and skills for a chosen occupation. Universities of applied sciences have a professional orientation and provide theoretical and practical training, whereas universities have an academic orientation and focus on training in academic disciplines.

Measures

Family networks

Participants were questioned about their family networks using the Family Network Method – Intellectual Disability (FNM-ID; Giesbers et al., 2019). To ensure that the data collected with participants with mild intellectual disability and students would be comparable, both groups were interviewed using the FNM-ID. The FNM-ID maps the family network, and measures the significant family members of the participant and the family members who provide emotional support. It contains four steps. First, participants are asked to map their family network. Participants are instructed to use their own definition of the term "family" and to define who they consider to be their family. As such, participants may use not only broader, but also more narrow definitions than more traditional definitions of the concept of family. They may, for example, include friends and can leave out biological family members (such as siblings) if they do not "feel" like family. To avoid priming participants' answers, this instruction does not contain examples of relationship types that could be included in the family network. The names of the listed family members are written down on separate cards, including a card with the name of the participant. Second, participants are instructed to define their significant family members from all members listed at step one. In a third step, questions about the provision of emotional support are asked. Participants are not only asked about their own relationships with their family members (in terms of emotional support), but are also asked to consider the relationships that exist between all family members. That is, after participants are asked about which family members they feel supported by when they "feel out of sorts", the same question is asked in relation to all other members of family network. For example, participants are asked: "When your mother is feeling out of sorts, who is there for her?" Last, participants are asked to assess their own significance from the perspective of their family members. Additionally, key demographic data about all listed family members (e.g., sex, age, place of residence) are collected.

Cognitive ability

The subtests 'Vocabulary' and 'Matrix Reasoning' of the WAIS-IV-NL were administered to participants with mild intellectual disability only (Wechsler, 2012). An estimation of their IQ-scores was made (see Procedure) to check whether they met the inclusion criterion of having an IQ between 50 and 70. This estimation was made based on subtest standard scores. The subtests 'Vocabulary' and 'Matrix Reasoning' correspond with the two-subtest form of the WASI-II (Wechsler, 2011). The WASI-II is an abbreviated version of the WAIS-IV and serves as a screening tool and brief measure of intelligence. As no Dutch version of the WASI-II is available, the two corresponding WAIS-IV-NL subtest were used in this study. This additional check on mild intellectual disability was included

in the study, as file scores were often outdated, obtained with different IQ measurements, or missing.

Procedure

Ethical approval was obtained from the Ethical Review Board of Tilburg University (EC-2015.46). The 53 participants with mild intellectual disability were part of a larger sample of 150 individuals with mild intellectual disability aged 18 – 40 years (Giesbers et al., 2019). For the current study, they were selected from the larger sample based on the criterion that they were aged between 18 and 25 years as a match with the student sample in the emerging adulthood period. The 150 participants with mild intellectual disability of the original sample were randomly selected from five organisations providing services to people with intellectual disability. A stratified sampling procedure was used; of each participating service provider, ten percent of service users who met inclusion criteria participated in the study. The inclusion criteria were: 1) a mild intellectual disability (IQ 50-70) according to file records, 2) aged between 18 and 40 years, and 3) receiving professional support from the service provider at least once a week for a minimum of six months. Participants with mild intellectual disability were always approached in consultation with support staff. First, the aims and procedure of the study were explained to staff on the telephone. Afterwards, an information letter was sent to staff and they were asked to discuss the information letter with the selected service users. This letter included information about the aims and content of the study, and the confidentiality of the data.

Staff of 354 individuals who met inclusion criteria were asked to invite the selected service users to participate in the study, of which 150 participated (42.4%). With those service users who were willing to participate, an appointment was scheduled at their home or, if preferred, another location within the service provider's facilities. Data were collected by the first author, the fifth author, and a research assistant. Participants were visited individually by the researcher for the duration of approximately 45 to 60 minutes per visit. Each visit started with smalltalk to put the participant at ease.

A standard consent procedure was followed to ensure that participants with mild intellectual disability could provide their informed consent (Arscott et al., 1998). After explaining the research project to participants (both verbally and with written information), the researcher determined whether they could recall: (i) the general content of the questions; (ii) how many times they would be interviewed, (iii) possible positive and negative aspects regarding participation, and (iv) that they could withdraw from the study at any time (without explanation). If needed, the researcher explained these four points in simpler or alternative words until the participant had an understanding of the key aspects of the study.

After participants gave their informed consent, WAIS-IV-NL subtests were administered, following the prescribed procedure. Next, demographic data were collected. During the last and main part of the visit, participants were questioned about their family network using the FNM-ID. After participation, standard scores for the WAIS-IV-NL subtests were computed. A participant was not considered to have mild intellectual disability when the standard scores on both subtests were outside the mild intellectual disability range (taking the reported standard errors into account). As a result, data from eleven participants were excluded (including seven participants aged 18-25 years) from the dataset.

Inclusion criteria for students were that they: 1) had moved out the family home, 2) were aged between 18 and 25 years, and 3) were attending post-secondary education (i.e., vocational training, university of applied sciences, university). First, students from the three levels of post-secondary education were included proportionally, based on the student numbers per level of education that exist in Dutch post-secondary education (Centraal Bureau voor de Statistiek, 2017). Also, it was ensured that students would be comparable to the subsample of participants with mild intellectual disability in terms of age and sex. Therefore, age was categorised into two categories (18-21 and 22-25 years), after which the existing proportions of male and female participants within both age categories were calculated for the subsample of participants with mild intellectual disability. Statistical testing showed that there were no significant differences between the sample of students and participants with mild intellectual disability in terms of age in years, $t(104) = -0.74$, $p = .462$, and sex, $\chi^2(1) = 0.16$, $p = .689$.

The 53 students were from nine post-secondary educational institutions located in seven different cities throughout the Netherlands. They were recruited by a contact person from their educational institution or face-to-face by the researcher. When recruited by a contact person, students who were willing to participate gave their permission to provide the researchers with their contact details, after which the researcher contacted them by telephone to explain the study and to schedule an appointment for a face-to-face interview. Also, an email was sent to students to confirm the appointment and to send them an information letter. Interviews were held at the educational institution or at the homes of participants. When students were recruited face-to-face at their educational institution, the interview took place at the same time as recruitment. The researcher first explained the aim, content and confidentially of the study after which participants were given the opportunity to read the information letter and ask questions concerning participation.

At the start of each interview, the informed consent form was signed after which participants were questioned about their family network using the FNM-ID. Also, demographic information (e.g., sex, age, level of education) was collected for each participant.

Data Analysis

Family network data were entered into Excel and analysed using UCINET (Version 6.623; Borgatti, Everett, & Freeman, 2002). Several social network measures, of interest within a social capital theoretical perspective, were computed (Giesbers et al., 2019) (see Table 1). Also, the type of family relationship was measured for the significant and supportive/supported family members. Next, UCINET output was imported into SPSS for the group comparisons (carried out using independent sample *t*-tests and chi-square tests).

Results

Network Measures

Independent samples *t*-tests were conducted to examine differences in the characteristics of the family networks of participants with mild intellectual disability and students (see Table 2).

With regard to the network measures (i.e., measures concerning the network as a whole), family networks of participants with mild intellectual disability and students

Table 1. Overview of the Computed Social Network Measures

Network Measures – full network	Size	Number of listed family members
Network measures – significant network	Size	Number of significant family members
	Density	The number of relationships between network members compared to the maximum possible numbers of relationships that could theoretically exist between all family members. For example, in highly dense networks, (nearly) all members are interconnected
	Dyad Reciprocity – all relationships	The number of dyads in the network with reciprocal relationships, divided by the total number of adjacent dyads in the network. For example, in networks with a high reciprocity, (nearly) all support relationships are mutual
Individual family network measures for participants	In-degree	Number of relationships in which the participant receives support
	Out-degree	Number of relationships in which the participant provides support
	Betweenness centrality	It quantifies the number of times a network member acts as a bridge along the shortest path between two other network members
	Dyad Reciprocity – relationships of participant only	The number of dyads (in which the participant is an actor) with reciprocal relationships, divided by the total number of adjacent dyads (in which the participant is an actor)

Table 2. Mean Numbers of the Network Measures for Participants, *t*, *p*, Cohen's *d*

	Variable	Mean (*SD*)		*t*	*p*	Cohen's *d*
		Individuals with MID (*n* = 53)	Students (*n* = 53)			
Full network	Size	9.85(5.54)	14.11(7.12)	-3.44	.001	.67
Significant network	Size	6.15(4.37)	10.17(7.11)	-3.51	.001	.68
	Density	0.37(0.24)	0.31(0.16)	1.65	.101	-.29
	Dyad Reciprocity – all relationships	0.42(0.30)	0.52(0.23)	-1.92	.057	.37
Measures for participants	In-degree	2.47(1.61)	4.02(4.18)	-2.52	.014	.49
	Out-degree	3.34(3.42)	5.53(4.32)	-2.89	.005	.56
	Dyad Reciprocity – relationships of participant only	0.32(0.30)	0.47(0.29)	-2.50	.014	.51
	Betweenness centrality	10.94(24.49)	39.42(75.72)	-2.61	.011	.51

were found to differ significantly in terms of size, with a medium to large effect size (Cohen, 1988). That is, participants with mild intellectual disability had significantly smaller family networks, t (104) = - 3.44, p = .001, and listed fewer significant family members, t (86.34) = - 3.51, p = .001. Despite small to moderate effect sizes, differences in network density, t (91.69) = 1.65, p = .101, and dyad reciprocity were not statistically significant, t (97.46) = - 1.92, p = .057.

Individual Family Network Measures for Participants

The two subsamples differed on all individual network measures, with medium sized effects (Table 2). Participants with mild intellectual disability had fewer relationships with family members in which support was received (i.e., in-degree), t (67.17) = - 2.52, p = .014, or given (i.e., out-degree), t (104) = - 2.89, p = .005, than students had. Also, participants with mild intellectual disability experienced their relationships with family members as less reciprocal than students did, t (104) = - 2.50, p = .014. Finally, participants with mild intellectual disability perceived themselves to be in a less central position in their family network, t (62.76) = - 2.61, p = .011.

Composition of Family Networks

Chi-square tests or, in case of low cell frequency, Fisher's exact tests were conducted to assess differences in the composition of the significant family network. Table 3 shows

Table 3. Types of Relationship in the Significant Family Network, χ^2, *p*, phi

Type of relationship	*n* (%)		χ^2	*p*	phi
	Individuals with MID (*n* = 53)	Students (*n* = 53)			
Partner	10(18.9)	21(39.6)	5.52	.019	.23
Parent	46(86.8)	46(86.8)	0.00	1.000	.00
Child	1(1.9)	0(0.0)	--	1.000(#)	-.10
Sibling	37(69.8)	48(90.5)	7.19	.007	.26
Extended family	33(62.3)	40(75.5)	2.16	.142	.14
Family in-law	11(20.8)	7(13.2)	1.07	.301	-.10
Step family	11(20.8)	6(11.3)	1.75	.186	-.13
Foster family	5(9.4)	2(3.8)	--	.437(#)	-.11
Friends	4(7.5)	22(41.5)	16.51	< .001	.40
Others	7(13.2)	5(9.4)	0.38	.540	-.06

Fisher's exact test

that, compared to students, a significantly smaller proportion of participants with mild intellectual disability included a partner, χ^2 (1) = 5.52, p = .019, sibling, χ^2 (1) = 7.19, p = .007, or friend, χ^2 (1) = 16.51, p < .001, in their significant network. These differences were small to medium effect sizes for partners and siblings and medium to large for friends (Murphy & Myors, 1998).

Group differences in the composition of support relationships were also assessed. Table 4 shows the proportion of participants with mild intellectual disability and students that reported at least one supportive (i.e., in-degree) or supported (i.e., out-degree) relationship within each family relationship category. Participants with mild intellectual disability were less likely to report receiving support from partners, χ^2 (1) =6.99, p < .008, and friends, χ^2 (1) = 18.90, p < .001. These differences were associated with medium sized effects for partners and medium to large sized effects for friends (Murphy & Myors, 1998). Participants with intellectual disability were also less likely to report giving support to partners, χ^2 (1) = 5.52, p < .019, friends, χ^2 (1) = 15.73, p < .001, parents, χ^2 (1) = 5.53, p < .019, and siblings, χ^2 (1) = 10.10, p = .001. Effects for partners and parents were small to medium, effects for siblings were medium, and effects for friends were medium to large in terms of size.

Table 4. Type of Relationship in terms of Received Support (in-degree) and Given Support (out-degree), χ^2, *p*, phi

Measure	Type of relationship	*n* (%)		χ^2	*p*	phi
		Individuals with MID (*n* = 53)	Students (*n* = 53)			
In-degree	Partner	8(15.1)	20(37.7)	6.99	.008	.26
	Parent	39(73.6)	34(64.2)	1.10	.294	-.10
	Child	0(0.0)	0(0.0)	--	--	--
	Sibling	16(30.2)	24(45.3)	2.57	.109	.16
	Extended family	15(28.3)	9(17.0)	1.94	.164	-.14
	Family in-law	5(9.4)	3(5.7)	--	.716(#)	-.07
	Step-family	4(7.5)	2(3.8)	--	.678(#)	-.08
	Foster family	4(7.5)	1(1.9)	--	.363(#)	-.13
	Friends	3(5.7)	22(41.5)	18.90	< .001	.42
	Others	4(7.5)	2(3.8)		.678	-.08
Out-degree	Partner	10(18.9)	21(39.6)	5.52	.019	.23
	Parent	24(45.3)	36(67.9)	5.53	.019	.23
	Child	1(1.9)	0(0.0)	--	1.000(#)	-.10
	Sibling	24(45.3)	40(75.5)	10.10	.001	.31
	Extended family	21(39.6)	23(43.4)	0.16	.693	.04
	Family in-law	6(11.3)	5(9.4)	0.10	.750	-.03
	Step-family	2(3.8)	3(5.7)	--	1.000(#)	.04
	Foster family	3(5.7)	0(0.0)	--	.234	-.17
	Friends	5(9.4)	23(43.4)	15.73	< .001	.39
	Others	5(9.4)	4(7.5)	--	.000(#)	-.03

Fisher's exact test

Discussion

This study examined the views of emerging adults with mild intellectual disability about their family support networks and compared these views to those of students without intellectual disability of the same sex and age, within a social capital theoretical framework.

We found that the family-based social capital of emerging adults with mild intellectual disability differed from that of students without intellectual disability. First, family networks of participants with mild intellectual disability consisted of fewer members, and in line with previous research (Widmer et al., 2008), participants with mild intellectual disability reported fewer "significant" family members than students without intellectual disability. More specifically, they significantly were less likely to include peers (i.e., friends and romantic partners) and siblings as significant family members.

Furthermore, participants with mild intellectual disability had significantly fewer relationships with family members in which they received support (associated with a medium effect size). This is an important finding, given that they may be particularly dependent on the support of significant others (Thompson et al., 2009). In addition, in recent times when there have been cuts in services, individuals with intellectual disability have become increasing reliant on their informal supportive networks for their social capital (Simplican, Leader, Kosciulek, & Leahy, 2015). However, the current findings show that emerging adults with mild intellectual disability felt they had less access to supportive resources from the family, potentially resulting in a more vulnerable position.

Moreover, participants with mild intellectual disability had significantly fewer relationships where they felt that they provided support to family members (a medium effect size difference). Participants with mild intellectual disability were less likely to report relationships with peers and nuclear family members (i.e., parents and siblings) that involved them supporting the family member. Also, their relationships with family members were less likely to be reciprocal. Reciprocity is one of the key features of social capital (Bullen & Onyx, 1999), and research has shown that opportunities to provide support for others and to have reciprocal relationships have been associated with feelings of self-worth, and better mental and physical health (Forrester-Jones & Barnes, 2008; Liang, Krause, & Bennett, 2001; Thomas, 2010). People with intellectual disability have also stressed the importance of reciprocity to make them feel useful, and to challenge feelings of dependence (Milner & Kelly, 2009). However, in line with the findings of the current study, they have also indicated that they often experience that their relationships are not based on reciprocity (Milner & Kelly, 2009). To contribute to feelings of self-worth and to challenge feelings of dependence, staff could focus on the support that people with intellectual disability may be able to offer to their significant others. In addition, reciprocity helps to ensure continuing relationships and exchanges (Bullen & Onyx, 1999).

The current findings suggests that, contrary to the pattern that is found in the general population (Aquilino, 2006; Conger & Little, 2010; Fraley & Davis, 1997; Tanner, 2006), the supportive networks of emerging adults with mild intellectual disability have not necessarily made the transition to networks that are more centred around peers, with emotionally close peer relationships. Compared to students without disability, the differences in the inclusion of significant and/or supportive/supported friends were associated with large sized effects. This situation might be dissatisfying for young people with mild intellectual disability, as other research has shown their wish for closer relationships with peers (Friedman & Rizzolo, 2018; Giesbers, Hendriks, Jahoda, Hastings, & Embregts, 2018; Healy, McGuire, Evans, & Carley, 2009; Rushbrooke, Murray, & Townsend, 2014). In particular, the lack of a romantic partner can make some individuals

feel unable to achieve the ordinary future they want, including settling down and having a family of their own (Neuman & Reiter, 2017; Rushbrooke et al., 2014). Thus, our findings suggest that emerging adults with mild intellectual disability remain more dependent on their natural family for emotional support, while they themselves were less likely to have a supportive role in their nuclear family (i.e., for parents and siblings), and support was less reciprocal compared to the students without intellectual disability. This finding is important, since positive effects of reciprocity on caregiver well-being have been shown in several studies (Carruth, Tate, Moffett, & Hill, 1997; Heller, Miller, & Factor, 1997; Reid, Moss, & Hyman, 2005). For example, Heller et al. (1997) found that when parents experienced greater support from an adult child with intellectual disability they experienced less burden and higher levels of caregiving satisfaction.

Contrary to Widmer's et al. (2008) study, participants with a mild intellectual disability in the present study did not perceive their significant networks to be less dense (and this was associated only with a small effect size), but they did perceive themselves to be in a less central position in their family network. That is, compared to students without intellectual disability, participants with intellectual disability fulfilled less of a "broker" role in their network. These findings mean that participants with mild intellectual disability experienced similar levels of bonding social capital compared to students without intellectual disability, while experiencing a lower level of bridging social capital. It might be possible that the presence of an intellectual disability hinders the development of social relationships that require reciprocity (e.g., friends and more extended family) (Cornwell, 2009; Gouldner, 1960). It are these types of relationships in particular that could give rise to bridging social capital (Aeby, Widmer, & De Carlo, 2014). They enable the individual to fulfil a "broker" function in their network in which they could mediate the flow of resources among network members, entailing feelings of autonomy and control (Burt, 1995). Because of the lack of these reciprocal relationships, the presence of an intellectual disability may lead to more restricted social networks with greater interconnectedness among its members (Cornwell, 2009). Consistent with this prediction, in the current study participants with mild intellectual disability did perceive their significant networks as smaller, but they did not perceive their network as more interconnected. Decreased levels of bridging social capital may hinder the autonomy of emerging adults with mild intellectual disability within their families (Woolcock, 1998). It is important for staff and service providers to recognise this finding when encouraging informal support.

The current findings should be considered within the limitations of the study. First, there is a risk of non-response bias. Only 42.4% of the randomly selected individuals with mild intellectual disability (18-40 years) participated in the overarching research, and this may also have negatively affected the representativeness of the sub-sample

of participants with mild intellectual disability aged 18-25 years. Furthermore, the study concerned a specific group of participants with mild intellectual disability; they all lived apart from family, with frequent support from paid staff. Future research should address emerging adults with mild intellectual disability living with their natural family or in other types of support arrangements. Also, future studies might also include people with a borderline level of functioning, to examine possible differences in the family-based social capital of people with mild intellectual disability and people with a borderline level of functioning. In the Netherlands, they are often approached as a homogenous group in policy and practice. However, even though they may experience (partly) overlapping support needs, significant differences may also exist between these groups, in terms of their vulnerability and the complexity of their support needs (Nouwens, Lucas, Smulders, Embregts, & Van Nieuwenhuizen, 2017). As such, it might be important to assess how their family structures may be functionally similar or different. Second, all participants without mild intellectual disability were students of post-secondary education, making the comparison group a selected group of emerging adults. Even though three educational levels were (proportionally) represented in the current study, it would be important for future studies to include a randomly selected sample of adults that may, for example, also involve emerging adults who do not or did not follow (post-secondary) education, or have already made the transition to work. In addition, participants with mild intellectual disability and students were compared only on age and sex. We did not collect data on how these two groups compared on other variables. As such, we were unable to examine whether differences in family-based social capital could be attributed to the presence of an intellectual disability or whether other factors accounted for these differences. For example, it would be important for future research to explore how work and school activities of emerging adults with and without intellectual disability relate to their social capital, as work and school settings provide increased opportunities to meet other people and foster social relationships beyond the nuclear family (Van Asselt-Goverts et al., 2013), while available social capital may also increase work and schooling opportunities (Timmons, Hall, Bose, Wolfe, & Winsor, 2011). An examination of factors associated with social capital is important, as it may lead to valuable insights into the need and opportunities for social capital creation for people with mild intellectual disability. Furthermore, the only information available about the FNM-ID currently is the face validity of the findings in previous studies and that participants are able to meaningfully complete the process (Giesbers et al., 2019). Free recall techniques of network data have generally shown good scores of reliability and validity (Ferligoj & Hlebec, 1999), and the original FNM has demonstrated test-retest reliability (Monney, 2007). Future studies should further evaluate the psychometric properties of the FNM-ID. Finally, to avoid priming participants' definition

of their family, examples of relationship types that could be included in the family network are not provided during the FNM-ID. As concrete thinking might have been more prevalent amongst participants with mild intellectual disability (Finlay & Lyons, 2001), the lower number of friends in their family networks could be related to the fact that friends do not fit the traditional definition of "family", and, therefore, were less likely to be included in the networks of young people with mild intellectual disability. In future research, this point could be examined by giving all participants information about who they might consider to be family. This potential effect of concrete thinking is clearly not universal for those with intellectual disability since 10 (18.9%) participants with mild intellectual disability included at least one family member that did not fit the traditional definition by including friends, neighbours, friends of parents, and their parents' support staff.

Despite these limitations, this study adds to family support and social capital theory by demonstrating how the family support experiences of young adults with mild intellectual disability differed from those of people without disabilities. Thereby, this study stresses the importance of examining the self-reported support experiences of people with mild intellectual disability. By examining how emerging adults defined their broad family group and how they perceived that their relationships within their family were intertwined, it provides a broader understanding of the network structures in which they are embedded, and the social capital available to them.

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CHAPTER 7

7

General discussion

The Current Thesis

In recent years, there has been increasing recognition that people with intellectual disability are full citizens with the same rights as people without disability, and participation and social inclusion have dominated the policy discourse within western society (e.g., Hewitt, Nord, Bogenschutz, & Reinke, 2013). To experience social inclusion, it is important to belong to a social network within one receives and contributes support (i.e., access to social capital; Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012). Previous research has shown that professionals continue to play a vital role in the supportive networks of people with mild intellectual disability, even when they live and participate in the community (e.g., Van Asselt-Goverts, Embregts, & Hendriks, 2013). Alongside paid staff, family members are often the key agents in their social networks (e.g., Van Asselt-Goverts et al, 2013). Families are often the main source of informal support and may also fulfill an important role in promoting people's social inclusion, as they may be the primary source for expanding the social network to members in the local community (Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014).

People with mild intellectual disability themselves are the experts and authorities on their own lives, experiences, and feelings (McDonald, Kidney, & Patka, 2013). However, existing family research has focused mainly on the impact of having a child with intellectual disability on parental well-being or family quality of life (Hastings, 2016), and has seldom considered their own experience of family support. Furthermore, studies on professional support have not provided an in-depth account of people's experiences with support from staff in the context of their broader lives and social circumstances.

As such, the first aim of this thesis was to contribute to our understanding of the family support experiences of people with intellectual disability, within a social capital theoretical perspective. More specifically, this thesis was concerned with the family relationships of adults with mild intellectual disability who had left their family home and were living with the support of a residential service provider. The focus was on the perceptions of people with mild intellectual disability themselves. To interpret the family support experiences of people with mild intellectual disability within the broader context of living with support from paid staff, the second aim of this thesis was to establish an in-depth account of the experiences of people with mild intellectual disability with respect to living with professional support. A broader understanding of the lives of people with mild intellectual disability who are supported by paid staff was provided, to better understand why professionals continue to play such a significant role for people and to interpret people's views of family relationships, within the broader context of living with support from paid staff.

In this final chapter, the main findings of the thesis are summarized and integrated, and the strengths, limitations and implications for research, policy, and practice are discussed.

Main Findings and Interpretations

Adapted Family Network Methodology

The Family Network Method (FNM; Widmer, Aeby, & Sapin, 2013), an instrument developed for use in the general population, was successfully adapted to meet the linguistic and cognitive needs of people with mild intellectual disability (Finlay & Lyons, 2001). Adaptions were made based on painstaking piloting with 19 people with intellectual disability, resulting in the Family Network Method – Intellectual Disability (FNM-ID; Chapter 3). The FNM-ID was found to be able to examine the perspective of people with mild intellectual disability about their family support networks and to yield theoretically significant information about their family support experiences. The FNM-ID adopts a broader approach of the concept of family, rather than defining family in terms of dyadic relationships within the nuclear family. It not only questions a person about his or her own relationships with family members, it also maps the person's perspective on the relationships among all family network members (e.g., father – mother; mother – aunt; aunt – grandpa). As such, the FNM-ID leads to a broader understanding of the family context of structural interdependencies in which the relationships between people with mild intellectual disability and their close family members are embedded (Widmer, 2016). Using the FNM-ID, people with mild intellectual disability (Chapter 4, 5, 6) and their family members (Chapter 5) were interviewed about their perceptions on the family network. In addition, students without intellectual disability were questioned about their network with the FNM-ID (Chapter 6).

Definition of the Significant Family

Participants with mild intellectual disability were found to report a variety of family groups, including significant family members beyond the members of their nuclear family, such as step-family, extended family, and friends (Chapter 4). However, their parents played an essential role in their family-based social capital and participants tended to view their parents as their main source of emotional support. This finding is in line with family members' reports about more practical support (Sanderson, Burke, Urbano, Arnold, & Hodapp, 2017). Even though siblings were considered to be part of the family group of most participants with a mild intellectual disability (about 90%), a smaller proportion viewed their siblings as significant to them (70%), and only half of the participants reported having a supportive relationship with siblings. This finding

showed that siblings were more at a distance in the lives of people with mild intellectual disability compared to parents. These findings are important in terms of the sustainability of the family-based social capital of people with mild intellectual disability. Older parents may experience increasing health problems and lower levels of energy to provide support (Grey, Griffith, Totsika, & Hastings, 2015), and parents are likely to die before their offspring, so it is likely that parents will not be able to fulfill a key support role for the duration of their child's whole life. As such, the involvement of siblings in the lives of people with intellectual disability may be of great importance.

Access to Supportive Family Resources

The family-based social capital of participants (aged 18-25) was found to differ from that of students without intellectual disability (Chapter 6). Compared to students without intellectual disability, their family groups consisted of fewer significant family members, although their (smaller) family groups were perceived to be as dense as those of the students. Also, participants with mild intellectual disability perceived themselves to have a less central position in their family group, i.e., they fulfilled less of a "broker" role. These findings imply that, compared to students without intellectual disability, participants with mild intellectual disability perceived similar levels of bonding social capital in their families, while experiencing a lower level of bridging social capital. An explanation of this finding might be that the presence of an intellectual disability hinders the development of relationships that require high levels of reciprocity (e.g., friends and more extended family) (Gouldner, 1960; Cornwell, 2009), and especially these types of relationships could bring about bridging social capital (Aeby, Widmer, & De Carlo, 2014).

In addition, these participants felt they had less support from their family than students without an intellectual disability. In recent years, there has been increasing emphasis on informal support, and cuts to the level of professional support have made people with mild intellectual disability increasingly reliant on their informal supportive networks and family carers for their social capital (e.g., Malli, Sams, Forrester-Jones, Murphy, & Henwood, 2018; Miettinen, 2012; Woittiez, Eggink, Putman, & Ras, 2018). However, the current findings show that young adults with mild intellectual disability had fewer relationships with received support of significant others than those without intellectual disability. As they may remain dependent on the support of significant others in their lives for practical and socio-emotional support (Thompson et al., 2009), this may leave people with mild intellectual disability vulnerable, and professional support may still be essential for many of them.

The (Social) Value of Staff

Indeed, the qualitative study in this thesis, in which six individuals with mild intellectual disability living in community-based residential support settings were interviewed about their experiences with professional support, showed that they placed a high value on staff being people who were there for them (Chapter 2). For the majority of participants, relationships with staff were one of the closest and confiding social relationships they had. In line with previous studies, staff not only provided them with practical support, but also emotional support (Van Asselt-Goverts et al., 2013), and meaningful social contact and informal interactions that were not directly support-related (Kwekkeboom, De Boer, Van Kampen, & Dorrestein, 2006), and they talked about their relationships with staff in a sense that included friendship. The importance of relationships with staff seemed to be related to the fact that close and meaningful relationships with people in the wider community were not readily formed. Consistent with previous studies, participants reported experiences of stigma (Jahoda & Markova, 2004, Pelleboer-Gunnink, Van Weeghel, & Embregts, 2019), social exclusion, and loneliness (Gilmore & Cuskelly, 2014). In addition, as in previous studies (Friedman & Rizzolo, 2018; Healy, McGuire, Evans, & Carley, 2009; Rushbrooke, Murray, & Townsend, 2014), participants expressed their wish for more close friendships and/or intimate relationships.

The Absence and Value of Close Peer Relationships

In line with the findings described in the previous paragraph, the studies in Chapter 4 and 6 showed that friends and romantic partners were seldom part of the family network. Compared to the pattern in the general population (e.g., Aquilino, 2006; Conger & Little, 2010), the supportive networks of participants with mild intellectual disability do not include close emotional bonds with peers. Instead, they remain more dependent on their biological family for emotional support. People with mild intellectual disability are acutely aware that they are missing out on these types of relationships (Friedman & Rizzolo, 2018; Healy et al., 2009; Rushbrooke et al., 2014). Intimate relationships are a potentially significant source of social support (Soulsby & Bennett, 2015), and people with intellectual disability have described that intimate relationships were important to fulfill their needs for company, support, love and affection (Rushbrooke et al., 2014). Missing out on intimate relationships can also make people with intellectual disability feel unable to achieve the ordinary future they want, including settling down with a partner. This subject that has only recently received increasing attention in research (English, Tickle, & dasNair, 2018; Neuman & Reiter, 2017; Rushbrooke et al., 2014). When participants reported relationships with partners and friends, they were often based on reciprocal support (about 70% and 65% respectively)(Chapter 4).

This highlights the potential significance of intimate and close relationships with peers for people with mild intellectual disability, as reciprocity is one of the key features of social relationships and social capital (Bullen & Onyx, 1999).

Reciprocity of Support

Compared to students without intellectual disability, people with mild intellectual disability generally reported fewer relationships that involved them themselves supporting their family member and fewer mutually supportive or reciprocal relationships (Chapter 6). Even though participants with mild intellectual disability had, on average, an equal amount of relationships with family members in which support was given and/or received (Chapter 4), substantial differences within the group of participants existed in terms of given support. About one third of participants did not believe that they fulfilled a support role for anyone in their family network. Research has shown that an over-benefited position, with more received than given support, may have a negative influence on the individual's self-worth and self-esteem (Forrester-Jones & Barnes, 2008; Liang, Krause, & Bennett, 2001). People with intellectual disability have also indicated that reciprocal relationships help them to feel useful, and to challenge feelings of dependence (Milner & Kelly, 2009). On average, about 30% of participants' relationships with family members were considered reciprocal, though the percentage of reciprocal support varied depending on the type of family relationship (Chapter 4). For example, as described before, relationships with partners and friends were often considered reciprocal by people with mild intellectual disability, whereas relatively few relationships (13%) with extended family members were reciprocal. This latter finding seemed to be related to the relatively high number of unidirectional relationships with given support to extended family (e.g., aunts/uncles, cousins, grandparents, and nieces/nephews). This means that extended family seemed to be important members of the family group, who participants felt they supported. However, only a minority (about one-third) of participants included (significant) extended family in their network.

Thus, the current thesis found that few family relationships were viewed as reciprocal. In addition, even though confiding relationships with staff were highly valued by participants in the qualitative study (Chapter 2), at least one participant was very aware that 'friendships' with staff may not be considered reciprocal. In the study of Forrester-Jones et al. (2006) unidirectional relationships with staff were also apparent; participants cared deeply about staff and wished to thank them by sending cards or presents but were unable to do so because this was not allowed by the service provider. As such, it left few opportunities for them to reciprocate and, as in the current qualitative study, this was a source of discomfort. Moreover, Pockney (2006) found that the perceptions of staff and service users about their shared relationships did not converge, as staff seldom considered service users as friends.

(Different) Perceptions of Family members

The studies within the current thesis imply that people with mild intellectual disability have fewer mutually supportive or reciprocal relationships. Moreover, the study in Chapter 5 demonstrates that people's sense of reciprocity within family relationships was not always recognized by their family members. That is, the findings in Chapter 5 illustrate that participants with mild intellectual disability and their family members held similar views about the supportive resources available to the person with intellectual disability (i.e., number of significant family members and relationships with received support), though differed in their views about the support that was contributed by the person with mild intellectual disability and the reciprocity of support in their family relationships. That is, people with mild intellectual disability reported more relationships in which they provided support than their family members reported, also resulting in higher levels of reported reciprocity. This is an important finding; the experience of reciprocity helps people with mild intellectual disability to enhance their self-worth and self-esteem (Forrester-Jones & Barnes, 2008; Liang, et al., 2001). It is also important for family members to experience reciprocity in their relationships with their relative with intellectual disability. Several studies have found positive effects of reciprocity on caregiver well-being (Carruth, Tate, Moffet, & Hill, 1997; Reid, Moss, & Hyman, 2005; Heller, Miller, & Factor, 1997). In line with previous studies, the current findings show that people with mild intellectual disability and their family members may hold different views about family support and their views may not always share a reality (Bartle-Haring, Kenny, & Gavazzi, 1999). This highlights the importance of including multiple perspectives on the family relationships of people with mild intellectual disability.

Limitations and Implications for Future Research

The current thesis included both quantitative and qualitative research studies, whereby different research methods were used (i.e., in-depth interviews, structured interviews, (self-report) questionnaires). The main focus was on the perspective of people with mild intellectual disability themselves, as they are the experts on their own experiences and feeling (McDonald et al., 2013). No existing social networks instruments developed for people with intellectual disability have a specific focus on assessing support in family networks, or are designed to examine the broader social context of interdependencies among networks members. Therefore, based on thorough piloting (Chapter 3), the original FNM (Widmer et al., 2013) has been adapted for use with people with mild intellectual disability. The resulting FNM-ID has been successfully used to collect data in a relatively large sample of randomly selected people with mild intellectual disability

(Chapter 4, 5, 6), their family members (Chapter 5), and a comparison group of students without intellectual disability (Chapter 6). Despite these strengths, several limitations of the studies in this thesis should be discussed. While each study within this thesis had its own specific limitations, a number of general limitations could be addressed.

Sampling and Recruitment

A number of sampling issues relate to the generalisability of the current findings and are important to mention. Participants with mild intellectual disability were randomly selected from five organisations providing services to people with intellectual disability, and a stratified sampling procedure (i.e., stratified by service provider) was used to increase the representativeness of the sample. However, only 42.4% of those with a mild intellectual disability who were invited to take part in the study participated. Reasons for non-response were, for example, that the expected burden of participation would be too high or that family members did not agree with participation of their relative. As such, there is a risk that the (families of) non-respondent differed from the (families of) respondents. However, no data were available for the non-respondents and, as such, it was not possible to quantify the potential non-response bias by comparing participants with non-respondents, and the findings should be interpreted within the context of this limitation.

Additionally, based on the experiences of other researchers (Lennox et al., 2005), people with mild intellectual disability were always approached in consultation with key staff members. It was assumed that recruitment would be best achieved through direct contact with a key staff member of the person with mild intellectual disability (Lennox et al., 2005). Even though this strategy may have had a positive influence on the response of people with mild intellectual disability themselves (when invited), in 28.9% of the non-response support staff and/or psychologists advised against participation and the person with mild intellectual disability was not invited. It is self-evident that involving vulnerable groups in research needs careful ethical consideration to protect them from harm (Dalton & McVilly, 2004; Iacono, 2006). However, it is worth careful consideration, as people with intellectual disability were found to value research benefits (McDonald, Conroy, & Olick, 2016). For example, the opportunity to participate in research, especially when they are making the participation decision, could help them feel valued.

Last, the findings concerned a specific group of people with mild intellectual disability; all lived apart from their biological family with frequent support (at least once a week) from staff from a service provider. Future research should address the perspective of people with mild intellectual disability in different kinds of living settings and support arrangements. For example, it might be interesting for future research to examine the

family support networks of people who live independently with no or few professional support, or people who live with their family.

Families of People with Mild Intellectual Disability from Different Cultural Backgrounds

Like all Western countries, the Netherlands has become culturally diverse. Today, about 23% of the Dutch population has a migrant background, of which 53% non-Western (13% of the total population; Centraal Bureau voor de Statistiek, 2018). The largest groups of non-Western immigrants in the Netherlands are Turkish-, Moroccan-, Indonesian-, Surinamese-, and Antillean-Dutch. However, in our study the vast majority of participants had a Dutch cultural background. Future research should specifically address the family support networks of people with mild intellectual disability with different cultural backgrounds, for two main reasons. First, the cultural background of a person may affect various dimensions of family life (Dykstra et al., 2006; Jennings, Khanlou, & Su, 2014; McMichael & Manderson, 2004). For example, it has been shown that people with a migrant background may endorse norms of family obligation more strongly, and have more contact with their families compared with those without a migrant background (Dykstra et al., 2006), while for others supportive family networks may be lacking or fractured because of relocation and geographical distances (Jennings et al., 2014; McMichael & Manderson, 2004). Second, even though they increasingly apply for professional support from disability services (Ministerie van Volksgezondheid, Welzijn, & Sport, 2017), people with mild intellectual disability and a migrant background are still under-represented in formal support (Gilsing, Pels, Bellaart, & Tierolf, 2015). As such, they may be more dependent on support from family (Bulsink & De Gruijter, 2013).

Other Dimensions of Family Relationships

Within the literature, support is often differentiated into emotional and instrumental support. In the original Family Network Method (Widmer et al., 2013), family relationships are measured in terms of both types of support (emotional and instrumental), influence, and conflict. The current thesis focused on emotional support only, for conceptual and pragmatic reasons. First, perceived emotional support has been considered as the most significant in relation to physical and mental health related outcomes (Berkman, 1995; Thoits, 1995; Viswesvaran, Sanchez, & Fisher, 1999). Also, people have been found to attribute an emotional meaning to supportive behaviours that are instrumental in nature. That is, these instrumental supports show the person that people care for him or her (Semmer et al., 2008). Emotional and instrumental support were also found to have an interactive effect on well-being. That is, instrumental support only had a large, positive effect on the well-being of both the support provider and recipient when

providers were emotionally engaged and supportive as well (Morelli, Lee, Arnn, & Zaki, 2015). Second, early testing during the pilot phase of adapting the FNM method for people with intellectual disability suggested that asking them about both dimensions of support was overly complex and did not lead to different information for each dimension. For example, difficulties arose in differentiating instrumental from emotional support. Also, piloting showed that focusing only on emotional support within the family already placed a high demand on people with intellectual disability. However, it could be of interest for future research to develop ways to question people with mild intellectual disability about instrumental support as well, to examine how experiences of instrumental and emotional support are distinct, overlap, or interact for people with mild intellectual disability (Morelli et al., 2015), and to gain insight into how instrumental support could contribute to the well-being of people with mild intellectual disability and their families.

In addition, there is evidence that next to positive dimensions of family relationships (social capital), negative dimensions (conflict) are significantly related to the individual's psychological health (Widmer, Girardin, & Ludwig, 2018). As a primary resource of support, the family is vital for mental health. Concurrently, families may be a source of stress and negative interactions among members of the family network may occur. For example, in highly dense family networks, other family members may threaten the autonomy of the individual network members because of the risk for intrusion and control (Widmer, 2016). Even though literature on this topic is scarce, people with mild intellectual disability may also be at risk to experience parental/familial control and conflict-ridden familial relationships (Mill, Mayes, & McConnell, 2009; Walmsley, 1996), and challenged to attain autonomous, adult roles family roles. In the qualitative study of Walmsley (1996), for example, participants with intellectual disability emphasized the control parents exercised over their income and freedom of movement. As such, it is of interest for future research to systematically examine autonomy and possible conflict structures within family networks of people with mild intellectual disability.

Family Networks over Time

To date, research into the informal supportive networks of people with intellectual disability was mostly of a cross-sectional nature. Research has shown that family networks of, for example, people with psychiatric problems were less stable over time than the networks of people from the general population (Widmer, 2016). People with psychiatric problems were less able to maintain meaningful (familial) relationships over a longer period of time, which, in turn, may had a negative impact on their psychiatric problems. For people with intellectual disability, it is also important to monitor the stability of family networks over time, as people with intellectual disability may also

experience difficulties maintaining meaningful relationships (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). This research will give service providers and policy makers insight into the additional actions that may be needed to facilitate participation and social inclusion of people with mild intellectual disability, together with their significant family members.

Informal Networks of People with more Severe Levels of Intellectual Disability

Research on participation and inclusion has generally focused on people with mild intellectual disability, whereas people with more severe levels of intellectual disability are often not included (Verdonschot, De Witte, Reichrath, Buntinx, & Curfs, 2009). The current thesis also focused on the support experiences of people with mild intellectual disability. Supportive relationships are of great importance to all individuals, and this may even be more so for people with moderate or severe intellectual disability or profound intellectual and multiple disabilities (PIMD), since they depend on support of others in most or all domains of life (Ayres, Mechling, & Sansosti, 2013; Nakken & Vlaskamp, 2007). It has been suggested that the individual's level of functioning is associated with the composition of the social network (Robertson et al., 2001). However, until now, very little research has specifically addressed the informal supportive networks of people with more severe levels of intellectual disability. Forrester-Jones et al. (2006) examined the social networks of people with mild and moderate intellectual disability and showed that about 30% of the social networks consisted of contacts outside the context of the service provider, of which half were family. However, in the results of Forrester-Jones et el. (2006), the networks of people with moderate intellectual disability were not described separately from those of people with mild intellectual disability. It is important to gain more knowledge on the support experiences of people with moderate intellectual disability as well, from their own perspectives. Although the intention was to include people with a moderate intellectual disability in the developments of the FNM-ID, the piloting showed that the instrument remained too complex for them despite the adaptations. In particular, those with a moderate intellectual disability found taking the perspective of another family member too complicated and cognitively challenging. This finding might be due to the degree of their disability. Future research should explore ways of questioning people with moderate intellectual disability about their perceptions of their family networks. For example, previous work has shown the value of questioning people with moderate intellectual disability in a way that was close in time and place with the interview topic (Van der Meulen, Taminiau, Hertogh, & Embregts, 2018).

Also, very little research has addressed the informal networks of people with severe intellectual disability or PIMD. Existing research shows that the proportion of family

members in the informal networks of people with PIMD is far greater than for people with mild intellectual disability. Kamstra, Van der Putten, and Vlaskamp (2015) examined the nature and frequency of social contact of people with PIMD. Their study showed that the informal networks of people with PIMD consist of five people on average, and that the vast majority (about 80%) of the networks consists of family members. Parents play the primary role in these network, and, as people get older, not only the network size, but also the frequency of contact with network members decreases (Kamstra, Van der Putten, Post, & Vlaskamp, 2014). These findings imply that the informal networks of people with PIMD are very vulnerable in terms of sustainability. Therefore, it is also important to gain more knowledge on the informal supportive networks of people with PIMD.

Implications for Policy and Practice

The findings of this thesis also have implications for policy and practice. First, an increasing emphasis on informal support networks has led to major legislative changes in the Netherlands (2015) and other Western countries. The resulting cuts to professional support have made people with mild intellectual disability increasingly dependent on their families for their social capital (e.g., Malli et al., 2018; Miettinen, 2012; Woittiez et al., 2018). However, the current study shows that their family resources may be scarcer than those available for the general population (Chapter 6), while at the same time support demands may be higher (Thompson et al., 2009). As such, families of people with mild intellectual disability may experience increased burden and the support needs of people with mild intellectual disability may not be met, potentially resulting in a more vulnerable position in society. Professional support may still be vital for many people with mild intellectual disability.

An important role of professional support could be to facilitate meaningful social relationships with family members and significant others. However, the persistent culture in services for people with intellectual disability, especially in residential support settings, seems predominantly to be one of care, with staff prioritising care tasks over tasks to promote people's social inclusion (McConkey & Collins, 2010). In addition, staff may not fully acknowledge and agree with the meaning of social inclusion for people with intellectual disability (Clement & Bigby, 2009), and it might be important to make them aware of the needs and wishes of people with mild intellectual disability in this respect, and of their role in fostering meaningful social contact with significant others.

Furthermore, in line with previous studies (Abbott & McConkey, 2006; Van Asselt-Goverts, Embregts, Hendriks, & Frielink, 2014), our findings show that sufficient staff-time may be helpful for staff to carry out this role (Chapter 2). People with mild intellectual

disability may need support from staff to actively engage in exchanges with family and significant others. To foster positive relationships with family members and significant others, the focus could also be on the support that people with intellectual disability may be able to offer to their significant others, as reciprocity helps to build confiding and lasting social relationships (Bullen & Onyx, 1999). A number of studies showed a positive effect of reciprocity on caregiver well-being (Carruth et al., 1997; Heller et al., 1997; Reid et al., 2005), illustrating that reciprocity in care and support may be a mechanism that contributes to lasting and supportive relationships with family members and significant others. Staff could support people's continued engagement with family members and significant others in simple ways by, for example, making them feel welcome and encourage people with mild intellectual disability to invite them to visit (Francis, Blue-Banning, Haines, Turnbull, & Gross, 2016), or supporting people with mild intellectual disability to write messages, sending cards or buying presents for them to mark key occasions (Kuis, Hermsen, Van Heijst, Timmermann, & Embregts, 2018), or by supporting them to take a family member (e.g., a niece or a nephew) out for a trip (Kramer, Hall, & Heller, 2013).

Additionally, the findings of the study in Chapter 5 show that perceptions about family relationships from individual members may not necessarily converge. As such, when encouraging (reciprocal) family relationships, staff and services should not only focus on the views of people with mild intellectual disability themselves, but they should also pay attention to the experiences of their family members and significant others. To foster confiding relationships, it is important for staff to initiate a dialogue with both people with mild intellectual disability and their significant others, and stimulate them to share their individual experiences, needs, and wishes.

The current thesis also suggests that people with mild intellectual disability may experience difficulties in forming close and confiding relationships with people in the wider community (Chapter 2), and showed that romantic partners and close friends were seldom part of the family network (Chapter 4 and 6). Like the participants in Chapter 2, other researchers have also shown that people with intellectual disability wish to have more close friendships and/or an intimate relationship (Friedman & Rizzolo, 2018; Healy et al., 2009; Rushbrooke et al., 2014). Chapter 4 showed that friendships and intimate relationships could be a valuable source of reciprocal support. Together these findings show that more could be done to facilitate close relationships of people with mild intellectual disability and to maintain these relationships. It is important to equally value close relationships with peers with and without disability and not to overlook friendships with other people with intellectual disability (Knox & Hickson, 2001). Furthermore, it might be important to know and respect the person's needs and wishes with respect to close relationships and support hem to develop and maintain these

relationships (Friedman & Rizollo, 2018). In addition, the facilitation of practical aspects such as transportation and community access may contribute to the development and maintenance of close relationships of people with intellectual disability (Friedman & Rizollo, 2018). Last, schooling and work opportunities of people with mild intellectual disability may provide increased opportunities to meet other people and foster significant relationships beyond the family (Van Asselt-Goverts et al., 2013).

As in Chapter 2, people with mild intellectual disability have expressed their desire for an intimate relationship (e.g., Rushbrooke et al., 2014). Especially intimacy and sexuality of people with intellectual disability is a topic that is often overlooked (Brown, Croft-White, Wilson, & Stein, 2000). Intimate relationships can bring several benefits for the individual such as companionship, happiness, and increased self-worth, and thereby, can contribute to their quality of life (Neuman & Reiter, 2017; Rushbrooke et al., 2014). As such, it is important for staff and services, but also for family members, to recognize the value of intimate relationships for people with intellectual disability, and to support them in forging and maintaining these relationships. However, people with intellectual disability have talked about how overprotective and controlling behaviour (i.e., a climate of risk aversion) of staff and family members had a negative impact on their close relationships (Bates, Terry, & Popple, 2017; Healy et al., 2009). Staff pointed out to struggle with the balance between supporting opportunities to form close relationships, while also protecting vulnerable people from potential harm. As such, staff training and coaching with respect to facilitating close relationships may be needed, and this is an issue that has been highlighted by staff themselves (Evans, McGuire, Healy, & Carley, 2009).

Interventions aimed to develop, strengthen and maintain the family and wider informal network of people with mild intellectual disability may be necessary. However, little is known about the effectiveness of such interventions (Howarth, Morris, Newlin, & Webber, 2014). Howarth et al. (2014) conducted a systematic review on interventions to improve social participation of adults with intellectual disability. They included 11 studies, of which only six showed positive outcomes. They concluded that Person-Centered Planning (PCP) (Robertson et al., 2006), alteration of activity patterns (Ouellette, Horner, & Newton, 1994), and group programs including social skill training were effective elements of interventions (Ward, Windsor, & Atkinson, 2012). When focusing specifically on family relationships, a PCP approach resulted in a 2.4 times greater chance of having active contact with family and a family member in the social network (Robertson et al., 2006). Van Asselt-Goverts, Embregts, and Hendriks (2018) evaluated an intervention based on Person-Centered Planning (i.e., I know them!), and found preliminary evidence of decreased loneliness, enhanced social networks, increased awareness of themselves and their network, autonomy, increased participation, and

competence (i.e., social skills). In addition, more general social skill training may strengthen people's social behaviours and facilitate more reciprocal interactions with peers (Hughes et al., 2011; Kohler & Fowler, 1985). With respect to people's living setting, there is some evidence that moving from an institutional setting to a smaller community based setting increases contact with family (Chou, Pu, Kröger, Lee, & Chang, 2011), though others report limited or no positive effect on people's social relationships because of relocation to smaller, more individualized support settings (Bigby, 2008; McConkey, Bunting, Keogh, & Garcia Iriarte, 2019).

The Connecting People Intervention (CPI), an intervention that provides guidance to staff on how to effectively help people with intellectual disability to develop their social networks, was evaluated within a social capital theoretical perspective (Webber et al., 2019). Next to experienced social inclusion and well-being, they measured participants' access to social resources within their social network using the Resource Generator (Webber & Huxley, 2007; Van der Gaag & Snijders, 2005) and found that the CPI led to higher access to social capital, and higher experienced social inclusion and well-being over time. As a Resource Generator measures the resourcefulness of networks in general rather than the structures of relationships in which these resources are available, the FNM-ID might be a useful tool to add when evaluating interventions that are aimed at enhancing people's social capital.

Although several interventions have yield promising results for the social participation and inclusion of people with intellectual disability, it has not been determined yet how these interventions can be "scaled up" to create larger shifts in (the culture) within services (Amado, Stancliffe, McCarron, & McCallion, 2013). It may require investment in training staff to promote community interaction and reciprocity. For example, systematic training programs can be carried out, such as those utilized for 'active support' (Amado et al., 2013). Finally, participants viewed stigmatizing views as a barrier to forming friendships and intimate relationships with people in the wider community (Chapter 2). While self-reported attitudes towards people with intellectual disability in research appear fairly positive (e.g., Ouellette-Kuntz, Burge, Brown, & Arsenault, 2010; Pelleboer-Gunnink et al., 2019), people with intellectual disability and their families may still feel stigmatized (Ali, Hassiotis, Strydom, & King, 2012; Mitter, Ali, & Scior, 2019) and anti-stigma interventions may contribute to people's social inclusion. With respect to public views, findings suggest that more positive public views are related to increased social contact with community members (Blundell, Das, Potts, & Scior, 2016; MacMillan, Tarrant, Abraham, Morris, 2014; Scior, 2011). However, anti-stigma campaigns directly aimed at the views of the public are also found to be effective (Walker & Scior, 2013). More specifically, protest approaches in which the public is educated about inequalities experiences by people with intellectual disability (as opposed to interventions that

focus on the similarities between people with and without intellectual disability), are found to enhance the public's support of empowerment and discouragement of sheltering.

In Conclusion

The current thesis shows that social capital is a useful theoretical framework for understanding support in the family relationships of people with mild intellectual disability, including their own perceptions. Within the current thesis, a broader approach of the concept of family has been adopted, rather than defining family in terms of dyadic relationships within the nuclear family, and shows the value of examining more broadly how people with mild intellectual disability define their family context and how the relationships within their family context are intertwined. It has focused on one of the key aspects of social relationships: reciprocity. For researchers and professionals, it is of great importance to adopt a broad perspective when encouraging family support. It is also important to not only look at the support people with mild intellectual disability are able to receive from their significant others, but also how they can reciprocate. It is important for staff to initiate a dialogue with both people with mild intellectual disability and their significant others, and stimulate them to share their individual experiences, needs, and wishes to help build mutual relationships with significant others outside the context of the service provider and to enhance their social inclusion.

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Summary

The aim of this thesis was to examine support in the formal (e.g., professionals) and informal networks (e.g., family and friends) of people with mild intellectual disability (IQ 50-70), within a social capital theoretical framework.

Chapter 1

In the general introduction in Chapter 1 the background, societal context, and developments in the care and support of people with intellectual disability are described. Also, the social capital theoretical framework is introduced.

Background and societal context

From the late 1990s, the deinstitutionalization of disability services has dominated the policy discourse in the Netherlands. Even though the closure of institutions led to people with an intellectual disability living in the community (i.e., physical presence), they remained socially marginalised. People with intellectual disability still experienced social barriers with community members, such as stigma, discrimination and rejection. As a result, they still had few meaningful relationships with other community members and experienced little sense of belonging. Consequently, the focus of policy and research has shifted from physical to social inclusion. The "Convention on the Rights of Persons with Disabilities" was adopted by the United Nations in 2006. This convention was ratified by the Netherlands in 2016. The convention protects the human rights of people with disabilities and aims for "full and effective participation and inclusion in society" of people with disabilities. Social inclusion is about building relationships. Belonging to a socially supportive network is part of social inclusion, but it can also facilitate other components of social inclusion. For example, friendships may facilitate community participation through undertaking joint activities, which increases the chance to meet new friends. To enhance the social inclusion of people with intellectual disability, the focus of policy is directed towards supporting individuals to forge stronger links with their local community, with the aim of increasing informal networks of support. Previous research has shown that family members often play a central role in people with intellectual disabilities' social networks. Next to family, professionals often play an important part in their social networks.

Theoretical framework

Families are often the main provider of informal support. As such, families are considered a significant source of social capital. Social capital is defined as resources that flow to individuals from their membership of a durable social network. From this perspective, family relationships (i.e., family-based social capital) are expected to have a variety of

positive outcomes for the individual, such as promoting physical and mental health. The two main types of social capital are relevant with respect to family networks (see Figure 1). Bonding social capital refers to a group with a high density of connections in which all or most individuals are interconnected. As dense networks enhance expectations, obligations, and trust among its members, support within such a network becomes collective. Bridging social capital refers to weaker connections between subgroups of a network that give some individuals (i.e., brokers) the potential to mediate the flow of resources between group members. A 'broker' role may lead to feelings of autonomy, competence and control.

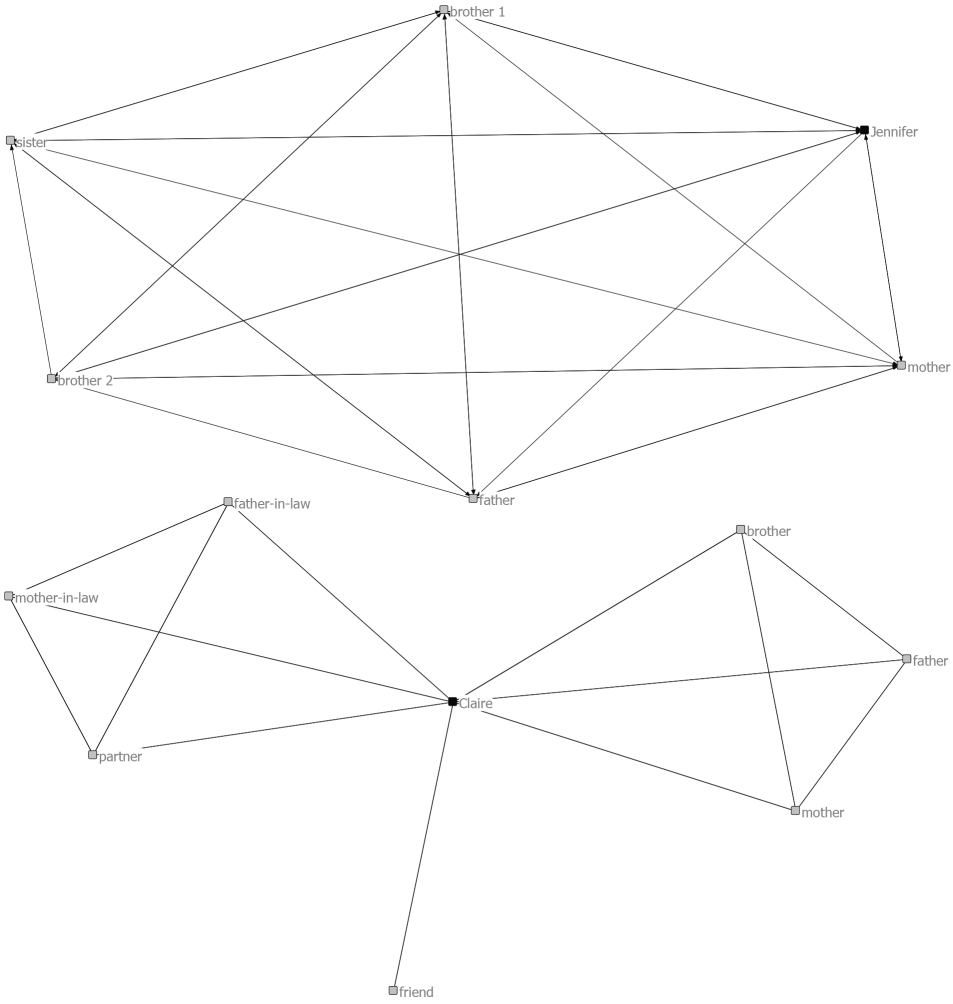


Figure 1. Bonding and bridging social capital

Another important theoretical concept related to the theory of social capital is the norm of reciprocity. Exchange within close relationships such as family members, may not require an "immediate return", but is based on the expectation that someone will return the favour sooner or later. However, for certain groups of people, such as children, the elderly, or people with disabilities, reciprocity might fail and the norm of beneficence appears, meaning that people support others regardless of the other's future ability to return the favour. Being able to provide support to other people may enhance feelings of self-worth and self-esteem, and an over-benefited position with more received than given support may have less favourable outcomes for the individual in terms of well-being and mental health than a more balanced position. Individuals with intellectual disability have also recognized reciprocity as a key feature of significant relationships and emphasized the importance of reciprocity in relation to their self-worth.

Aims of the thesis

Despite the recognition that families play a central role in the lives of people with intellectual disability, very little research has considered directly the perspective of people with intellectual disability about support within their families. Next, even though professionals continue to play a vital role in the lives of people with mild intellectual disability, even in a changing societal context of deinstitutionalization and inclusion, studies have not provided an in-depth account of people's experiences with professional support in the context of their broader lives and social circumstances.

As such, the first aim of this thesis was to contribute to our understanding of the family support experiences of people with intellectual disability, within a social capital theoretical perspective. More specifically, this thesis was concerned with the family relationships of adults with intellectual disabilities who had left their family home and were living with the support of a residential service provider. The focus was on the perceptions of people with mild intellectual themselves. The second aim of this thesis was to establish an in-depth account of the experiences of people with mild intellectual disability with respect to living with professional support. A broader understanding of the lives of people with mild intellectual disability who are supported by paid staff was provided, to better understand why professionals continue to play such a significant role for people and to interpret people's views of family relationships, within the broader context of living with support from paid staff.

Chapter 2

This Chapter describes a study in which the experiences of six individuals with mild intellectual disability with respect to living with professional support were examined.

In-depth accounts of participants' support experiences were established using the qualitative research method "Interpretative Phenomenological Analysis" (IPA). The goal of IPA is to address how individuals make sense of events or aspects of their lives which, in turn, are embedded in their broader personal histories and social contexts. For the majority of participants, relationships with support staff were one of the closest and most significant social relationships they had, with staff not only providing them instrumental support, but also emotional support, and significant and meaningful social contact. The results also showed that relationships with staff played a more central role in the lives of participants when they had few other friendships or close relationships. For the participants in this study, having few friends or social relationships appeared to be linked to feelings of exclusion and loneliness. They also expressed a wish for more friendships and/or an intimate relationship. Furthermore, participants were aware of stigma and described experiences of being treated differently or negatively. Participants viewed stigmatizing views as a barrier to forming friendships and intimate relationships with people in the wider community. Stigmatizing views were also related to participants' struggles with their identities. Paradoxically, the help and support they needed to lead their lives was what some participants felt that marked them out as different and, in their experience, "spoiled" their identity. Living in the community had not necessarily led to increased social capital or meaningful inclusion for the participants in the current study. Instead, staff continued to play a vital role in their social lives.

Chapter 3

This Chapter describes how the Family Network Method (FNM), a method to explore family relationships from a social capital theoretical perspective (developed for use in the general population), was adapted for use with people with mild intellectual disability. Based on thorough piloting with 19 individuals with intellectual disability, the original FNM has been successfully adapted to the Family Network Method - Intellectual Disability (FNM-ID) version. The instrument was structured and standardized, and visual and auditory supportive techniques were added to the interview protocol to support people with mild intellectual disability in answering the questions. The FNM-ID maps:

1. How the person with mild intellectual disability defines his/her (significant) family.
2. The emotionally supportive relationships (received and given support) that the person with mild intellectual disability perceives between himself/herself and his/her family members.
3. How the person with mild intellectual disability perceives the emotionally supportive relationships among all family members.

The FNM-ID does not predefine what constitutes the participants' families. As such, participants define their own families, whether narrower or broader of more traditional definitions of family. The FNM-ID not only offers a way to gather the perspective of people with mild intellectual disability about their family support, but also provides rich, theoretically significant information about the perceived structure of their family network (i.e., social capital). The FNM-ID provides information about the person's perception of the relationships amongst all family network members. Thus, the FNM-ID provides a broader understanding of the family context of structural interdependencies in which individuals with mild intellectual disability and their close family relationships are embedded. Supportive relationships between a person with intellectual disability and his/her family members cannot be seen as isolated from this broader family structure. Data obtained by the FNM-ID can be analysed using social network analysis; measures such as density, centrality and reciprocity can be calculated. Two cases are described to illustrate the utility of the FNM-ID.

Chapter 4

The study in Chapter 4 describes how 138 people with mild intellectual disability (18 – 40 years) define their family network. All participants had left their family home and were living with the support of a service provider. Participants were questioned using the FNM-ID. The findings of the study show that individuals with mild intellectual disability describe a variety of family groups, including significant family members beyond the nuclear family, such as extended family, in-laws, step-family, and friends. According to participants, the nuclear family of origin, and especially parents, played a prominent role in their social capital. That is, in total, participants had the highest number of relationships with parents and their parents were seen as the main support provider. Some individuals with mild intellectual disability also saw themselves as being supportive to their parents. In a few cases (10% of reported relationships with parents), participants thought that they were supportive of their parents even though they did not feel this was reciprocated. Siblings were considered to be part of the nuclear family by the vast majority (about 90%) of participants. However, smaller groups of participants considered their siblings as significant to them (70%), or felt a supportive connection with them; only half of participants reported a support relationship with (a) sibling(s). This finding shows that siblings were perceived to be more at a distance and this is important in terms of the sustainability of the family-based social capital of people with mild intellectual disability. It is likely that parents will not be able to fulfill a key support role for the duration of their child's whole life; older parents may experience increasing health problems and lower levels of energy to provide support, and parents are likely

to die before their offspring. As such, the involvement of siblings in the lives of people with intellectual disability may be of great importance. Another important finding was that partners and/or children were seldom part of participants' family networks. People with mild intellectual disability may often miss this potentially significant source of social capital. When partners were part of the family network, they were always considered significant.

As a group, individuals with mild intellectual disability did not have a sense that they receive more support from others than they give; on average, participants had an equal amount (both about 2.3) of relationships with family members in which support was given and/or received. However, there were substantial differences within the group of participants. About one third of participants did not believe that they fulfilled a supportive role for anyone in their family network. Moreover, only 30% of participants' relationships were perceived as reciprocal. The ratio of given, received or reciprocated support also varied by the type of family relationship. Even though the findings are based on relatively small numbers, relationships with partners and friends were often (about 70% and 65% respectively) based on mutual support. In contrast, participants had relatively few (13%) reciprocal relationships with extended family members (i.e., aunts/uncles, cousins, grandparents, and nieces/nephews). This seemed to be related to the relatively high number (70%) of unidirectional relationships in relation to support (i.e., given support by the participant). This means that participants felt that they could contribute support within this group, though only about one-third of participants included extended family in their (significant) family network.

Chapter 5

Chapter 5 describes the examination of the family support networks of people with mild intellectual disability (aged 18-40 years), by assessing both their own perceptions (n = 111) and the perceptions of their family members (n = 111), and comparing both perspectives on the key social network measures of interest within a social capital theoretical framework. In addition, factors associated with diverging perceptions were examined. All participants were questioned using the FNM-ID. In addition, 111 (key) support workers were included in the study as proxy informants on the behavioural and emotional problems of the participants with mild intellectual disability. The results of this study showed that participants with mild intellectual disability and their family members have different perceptions about several aspects of the family support network. Participants with mild intellectual disability and their family members did not differ in their estimations of the numbers of significant family members and relationships in which the person with mild intellectual disability received support. However, family

perceived the person with mild intellectual disability as less supportive to family members, with fewer reciprocal relationships and a less central position (i.e., bridging social capital) in the family network. Family members also perceived fewer relationships among all network members (i.e., bonding social capital) than the participants with mild intellectual disability. When the participant with mild intellectual disability displayed higher levels of externalizing behaviour problems, the divergence in perceptions of support provided by the person with mild intellectual disability became larger. It was also found that women with mild intellectual disability were significantly more likely than men to disagree with family members on their bridging social capital.

Chapter 6

The study in Chapter 6 examined the views of 53 young adults (18-25 years) with mild intellectual disability about their family support networks and compared these views to those of 53 (vocational training, university of applied sciences, university) students without intellectual disability of the same sex and age. Participants were questioned using the FNM-ID. The family-based social capital of young adults with mild intellectual disability differed from that of students without intellectual disability. First, family networks of participants with mild intellectual disability consisted of fewer members and participants with mild intellectual disability reported fewer "significant" family members than students without intellectual disability. More specifically, they significantly were less likely to include peers (i.e., friends and romantic partners) and siblings as significant family members. They also had fewer relationships with family members in which they received or gave support, and had fewer reciprocal support relationships. The results of this study show that young adults with mild intellectual disability remain more dependent on their nuclear family for emotional support as their supportive networks have not necessarily, like young adults without intellectual disability, made the transition to networks with emotionally close peer relationships. Moreover, they themselves were less likely to have a supportive role in their nuclear family (i.e., for parents and siblings). Last, this study showed that participants with mild intellectual disability experienced similar levels of bonding social capital compared to students without intellectual disability, while experiencing a lower level of bridging social capital.

Chapter 7

Finally, in the general discussion in Chapter 7, the main findings of the thesis are summarized and integrated, and the implications for policy and practice are discussed.

First, an increasing emphasis on informal support networks has led to major legislative changes in the Netherlands (2015) and other Western countries. The current study shows that their family resources may be scarcer than those available for the general population, while at the same time support demands may be higher. As such, families of people with mild intellectual disability may experience increased burden and the support needs of people with mild intellectual disability may not be met. Professional support may still be vital for many people with mild intellectual disability.

An important role of professional support could be to facilitate meaningful social relationships with family members and significant others. Interventions aimed to develop, strengthen and maintain the informal networks of people with mild intellectual disability seem to be necessary. However, the persistent culture in services for people with intellectual disability, especially in residential support settings, seems predominantly to be one of care. Existing network interventions have yield promising results for the participation and inclusion of people with intellectual disability and it is important to determine how these interventions can be "scaled up" to create larger shifts in (the culture) within services. It might be important to make staff aware of the needs and wishes of people with mild intellectual disability in this respect, and of their role in fostering meaningful social contact with significant others. To foster positive relationships with family members and significant others, the focus could also be on the support that people with intellectual disability may be able to offer to their significant others, as reciprocity may help to build confiding and lasting social relationships. A number of studies showed a positive effect of reciprocity on caregiver well-being. Staff could support people's continued engagement with family members and significant others in simple ways by, for example, making them feel welcome and encourage people with mild intellectual disability to invite them to visit, or supporting people with mild intellectual disability to write messages, sending cards or buying presents for them to mark key occasions, or by supporting them to take a family member (e.g., a niece or a nephew) out for a trip. Additionally, the current findings show that perceptions about family relationships from individual members may not necessarily converge. As such, when encouraging (reciprocal) family relationships, staff and services should not only focus on the views of people with mild intellectual disability themselves, but they should also pay attention to the experiences of their family members and significant others.

The current thesis also suggests that people may experience difficulties in forming close and confiding relationships with people in the wider community, and showed that romantic partners and close friends were seldom part of the family network. Participants had a wish for more close friendships and/or an intimate relationship. These relationships can bring several benefits for individuals such as companionship,

happiness, and increased self-worth, and thereby, can contribute to their quality of life. The results of this thesis showed that friendships and intimate relationships could be a valuable source of reciprocal support. Together these findings show that more could be done to facilitate close relationships of people with mild intellectual disability and to maintain these relationships.

Last, in Chapter 7, several strengths and limitations of the studies are discussed. The current thesis included both quantitative and qualitative research studies, whereby different research methods were used (i.e., in-depth interviews, structured interviews, (self-report) questionnaires). The FNM-ID provided insight into the family-based social capital of people with mild intellectual disability, with a focus on their own perceptions. Participants in the quantitative studies were randomly selected and a stratified sampling procedure was used. However, there is a risk of non-response bias and the findings should be interpreted within the context of this limitation. Also, the findings concerned a specific group of people with mild intellectual disability; all lived apart from their biological family, were frequently supported by staff from a service provider, and most had a Western cultural background. Future research should address the perspectives of people with mild intellectual disability who live with their family, who live independently with no or few professional support, or who have a non-Western cultural background. The current thesis focused on emotional support in family relationships. Future research could examine other dimensions of family relationships, such as instrumental support or conflict. It is also important for future studies to monitor the stability of family networks over time. Finally, future research should address support in the families of people with more severe intellectual disabilities.

Conclusion

The current thesis shows that social capital is a useful theoretical framework for understanding the role of family relationships in the lives of people with mild intellectual disability. For researchers and professionals, it is of great importance to adopt a broad perspective when encouraging family support. It is important to not only look at the support people with mild intellectual disability are able to receive from their significant others, but also how they can reciprocate. It is important for staff to initiate a dialogue with both people with mild intellectual disability and their significant others, to help build mutual relationships and to enhance their social inclusion.

Samenvatting

Het onderzoek in dit proefschrift richtte zich op het in kaart brengen van de ondersteuning die mensen met een lichte verstandelijke beperking (IQ 50-70) ervaren in hun formele (d.w.z. professionals) en informele netwerk (bijv. familie en vrienden), binnen het theoretische kader van sociaal kapitaal.

Hoofdstuk 1

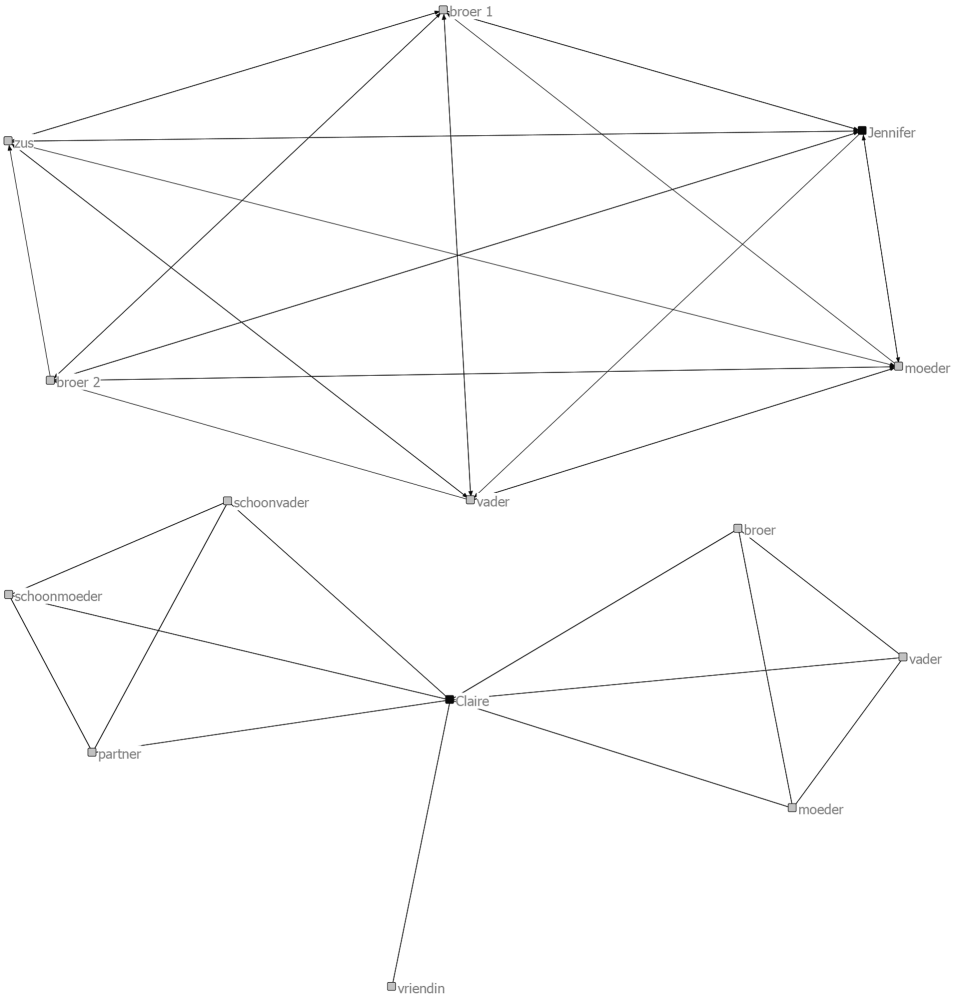
De algemene inleiding in Hoofdstuk 1 geeft een verkenning van de achtergrond, maatschappelijke context en de ontwikkelingen binnen de zorg voor mensen met een verstandelijke beperking. Ook wordt nader ingegaan op 'sociaal kapitaal' als theoretisch kader.

Achtergrond en maatschappelijke context

Vanaf het eind van de jaren negentig heeft het beleid van de overheid zich onder andere gericht op de-institutionalisering van de zorg voor mensen met een verstandelijke beperking. Hoewel het sluiten van instellingen ertoe leidde dat mensen met een verstandelijke beperking in toenemende mate in de samenleving woonden en participeerden (d.w.z. fysieke inclusie), werd al snel duidelijk dat er een kloof bleef bestaan tussen hen en andere mensen in de samenleving. Mensen met een verstandelijke beperking ervaarden nog steeds barrières in het aangaan van sociale contacten, zoals discriminatie, afwijzing of stigma. Hierdoor hadden zij weinig betekenisvolle relaties met andere mensen in de gemeenschap waar zij woonden en het gevoel onderdeel te zijn van de gemeenschap ontbrak. De focus van onderzoek en beleid verschoof daarom van fysieke inclusie naar sociale inclusie. In 2006 werd het "Verdrag inzake de rechten van personen met een handicap" door de Verenigde Naties aangenomen. Dit verdrag beschermt de rechten van mensen met een beperking en streeft naar "volledige en effectieve participatie en inclusie in de samenleving". Dit VN-verdrag werd in 2016 ook door Nederland geratificeerd. Het behoren tot een sociaal netwerk is een belangrijk aspect om sociale inclusie te ervaren. Onderdeel zijn van een sociaal netwerk is sociale inclusie op zichzelf, maar het kan ook verdere inclusie faciliteren. Zo kunnen sociale relaties, zoals vriendschappen, participatie vergemakkelijken door samen activiteiten te ondernemen, waardoor de kans op het leggen van nieuwe sociale contacten vergroot wordt. Om de sociale inclusie van mensen met een verstandelijke beperking te vergroten, is ook het huidige beleid en wet- en regelgeving gericht op het vergroten van de rol van hun sociale netwerk. Uit eerder onderzoek is gebleken dat familieleden een centrale rol spelen in de netwerken van mensen met een lichte verstandelijke beperking. Naast familieleden bestaan deze netwerken vaak voor een groot deel uit professionals.

Theoretisch kader

Familie is vaak de primaire bron van informele ondersteuning en wordt daarom gezien als een belangrijke vorm van sociaal kapitaal. Sociaal kapitaal verwijst naar de hulpbronnen die beschikbaar zijn in het netwerk van een persoon. Aangenomen wordt dat positieve en ondersteunende familierelaties de fysieke en mentale gezondheid van een persoon zullen bevorderen. Er zijn twee typen sociaal kapitaal te onderscheiden (zie Figuur 1). De eerste is verbindend (bonding) sociaal kapitaal. Er is sprake van verbindend sociaal kapitaal wanneer een netwerk bestaat uit veel onderlinge



Figuur 1. Verbindend en overbruggend sociaal kapitaal

verbindingen (d.w.z. een hoge dichtheid van relaties) waarbij veel, zo niet alle, leden van het netwerk met elkaar in verbinding staan. Deze netwerken worden vaak gekenmerkt door een hoge mate van vertrouwen en onderlinge verwachtingen en verplichtingen. Hierdoor wordt de ondersteuning binnen deze netwerken als het ware collectief: ondersteuning wordt vanuit een gezamenlijkheid geboden. De tweede vorm van sociaal kapitaal is overbruggend (bridging) sociaal kapitaal. Overbruggend sociaal kapitaal verwijst naar de positie van iemand binnen het netwerk en wel naar de mate waarin een persoon de verbindingsschakel is tussen subgroepen in een netwerk. Deze positie in het netwerk kan leiden tot gevoelens van autonomie, competentie en controle.

Ook wederkerigheid is een belangrijk begrip als het gaat om sociaal kapitaal. Wederkerigheid binnen hechte relaties, zoals familierelaties, betekent vaak niet dat men elkaar direct iets hoeft terug te geven. Deze relaties zijn vaak gebaseerd op de verwachting dat de ander op een later tijdstip ook klaarstaat en iets terugdoet en er over de langere termijn gezien een balans is tussen geven en nemen. Voor sommige groepen mensen, zoals kinderen, ouderen en mensen met een beperking is het mogelijk moeilijker om de ander iets terug te geven. Men ontvangt dan ondersteuning, zonder dat men in staat is deze ondersteuning ook aan de ander terug te geven. Het geven van ondersteuning is belangrijk voor het zelfbeeld en het gevoel van eigenwaarde van een persoon. Wederkerige relaties hebben dan ook een positiever effect op het welbevinden van een persoon dan relaties waarin men alleen steun ontvangt. Ook mensen met een lichte verstandelijke beperking hebben aangegeven dat het belangrijk voor hen is dat zij iets voor een ander kunnen betekenen.

Doelen van dit proefschrift

Hoewel familie een belangrijke rol speelt in het leven van mensen met een lichte verstandelijke beperking, heeft familieonderzoek zich tot op heden zelden gericht op de ervaringen van mensen met een lichte verstandelijke beperking zelf met betrekking tot de ondersteuning binnen de familie. Ondanks dat professionals ook binnen de veranderende maatschappelijke context een grote rol blijven spelen in het leven van mensen met een lichte verstandelijke beperking, ontbreekt in eerder onderzoek naar de ervaringen van mensen met een lichte verstandelijke beperking met professionele ondersteuning vaak een beeld van de bredere sociale context waarin deze ervaringen zijn ingebed.

Het eerste doel van dit promotieonderzoek was het in kaart brengen van de ervaringen van mensen met een lichte verstandelijke beperking met betrekking tot ondersteuning in hun familie, binnen het theoretische kader van sociaal kapitaal. Hierbij stonden de ervaringen van mensen met een lichte verstandelijke beperking die het ouderlijk huis hadden verlaten en woonden met begeleiding centraal. Om hun

ervaringen met betrekking tot familie te kunnen interpreteren in de bredere context van wonen met begeleiding, was het tweede doel van dit onderzoek om de ervaringen met het wonen met begeleiding op gedetailleerde wijze in kaart te brengen, opdat we beter kunnen begrijpen waarom begeleiders en andere professionals een belangrijke rol blijven spelen in het netwerk van mensen met een lichte verstandelijke beperking.

Hoofdstuk 2

Dit hoofdstuk beschrijft een studie waarin zes mensen met een lichte verstandelijke beperking werden bevraagd naar hun ervaringen met het wonen met begeleiding, volgens de kwalitatieve onderzoeksmethode "Interpretative Phenomenological Analysis" (IPA). IPA heeft als doel in kaart te brengen hoe mensen betekenis geven aan bepaalde gebeurtenissen of aspecten in hun leven en hoe deze ervaringen zijn ingebed in hun persoonlijke geschiedenis en sociale context. Voor de meeste participanten waren relaties met begeleiders een van de meest hechte en belangrijkste sociale relaties die zij hadden. Begeleiders boden hen niet alleen praktische ondersteuning, maar ook emotionele ondersteuning en betekenisvol sociaal contact. Relaties met begeleiders bleken belangrijker wanneer zij weinig andere hechte relaties hadden, bijvoorbeeld met vrienden. Voor de participanten in dit onderzoek bleek het hebben van weinig vrienden of sociale relaties samen te gaan met gevoelens van uitsluiting en eenzaamheid. Zij gaven aan graag meer vriendschappen of een romantische relatie te willen hebben. Ook beschreven participanten ervaringen van stigma en ervaringen waar zij als anders of negatief behandeld werden. Stigmatiserende opvattingen van mensen in de samenleving werden door de deelnemers gezien als een barrière voor het vormen van vriendschappen en hechte relaties met mensen in die samenleving. Het ervaren van stigma was ook gerelateerd aan het feit dat participanten moeite hadden met het ontwikkelen van een positieve identiteit. Paradoxaal was het gegeven dat de ondersteuning die de participanten nodig hadden om hun leven te kunnen leiden ook datgene wat hen als "anders" bestempelde en interfereerde met een positieve identiteitsontwikkeling. Voor de participanten in dit onderzoek leidde het wonen in de wijk niet automatisch tot meer sociaal kapitaal en een hogere mate van sociale inclusie. De relaties met begeleiders bleven onverminderd belangrijk voor hen.

Hoofdstuk 3

Dit hoofdstuk beschrijft de aanpassing van de Family Network Method (FNM), een methode om sociaal kapitaal in familienetwerken in de algehele populatie in kaart te brengen, voor mensen met een lichte verstandelijke beperking. Op basis van gedegen

pilotwerk met 19 mensen met een verstandelijke beperking werd de FNM aangepast tot de Family Network Method - Intellectual Disability (FNM-ID). Het instrument werd gestructureerd en gestandaardiseerd en voorzien van visuele ondersteuning en auditieve prompts om mensen met een lichte verstandelijke beperking te ondersteunen in het beantwoorden van de vragen. De FNM-ID brengt in kaart:

1. Wie een persoon met een lichte verstandelijke beperking als zijn/haar (belangrijke) familieleden beschouwt en voor wie hij of zij zichzelf belangrijk voelt.
2. Welke onderlinge verbindingen (in termen van emotionele ondersteuning) een persoon met een lichte verstandelijke beperking ziet en ervaart tussen zichzelf en zijn/haar familieleden.
3. Welke verbindingen een persoon met een lichte verstandelijke beperking ziet tussen zijn/haar familieleden onderling.

De FNM-ID kent geen vaststaande definitie van het begrip 'familie'. Respondenten bepalen zelf wie er voor hen als familie voelt of wie zij als familie zien. Als zodanig kunnen respondenten niet alleen bredere, maar ook nauwere definities gebruiken dan meer traditionele definities van 'familie'. De FNM-ID biedt niet alleen een manier om het perspectief van mensen met een lichte verstandelijke beperking over de ondersteuning binnen hun familienetwerk in kaart te brengen, het biedt ook belangrijke theoretische informatie over de structuur van het netwerk (d.w.z. sociaal kapitaal). Het instrument geeft inzicht in de ondersteuning die mensen met een lichte verstandelijke beperking ervaren vanuit hun familie, alsmede in de opbouw en structuur van de bredere familiecontext, inclusief alle onderlinge verbindingen en afhankelijkheden. Ondersteunende relaties tussen een persoon met een lichte verstandelijke beperking en zijn of haar familieleden kunnen niet als geïsoleerd van deze bredere familiestructuur gezien worden. De data verkregen door de FNM-ID kunnen worden geanalyseerd met behulp van sociale netwerkanalyse; maten als dichtheid, centraliteit en wederkerigheid kunnen berekend worden. In dit hoofdstuk wordt aan de hand van twee casussen tevens de toepasbaarheid van de FNM-ID geïllustreerd.

Hoofdstuk 4

De studie in hoofdstuk 4 beschrijft hoe 138 mensen met een lichte verstandelijke beperking (18 – 40 jaar) hun familienetwerk definiëren. Alle participanten hadden het ouderlijk huis verlaten en woonden met begeleiding. De participanten werden bevraagd middels de FNM-ID. Zij beschreven een diversiteit aan familierelaties, waaronder relaties met familieleden buiten het kerngezin, zoals ooms en tantes, schoonfamilie, stieffamilie en vrienden. Volgens de deelnemers speelde het kerngezin, en met name de ouders, een prominente rol in hun sociaal kapitaal. Dat wil zeggen, in totaal hadden participanten

de meeste relaties met ouders en ouders werden gezien als de belangrijkste bron van ondersteuning. Een deel van de participanten zag zichzelf ook als ondersteunend voor hun ouders. Eén derde van de relaties met ouders werd als wederkerig beschouwd. In enkele gevallen (10% van de relaties met ouders) gaven participanten aan dat zij ondersteunend waren voor ouders, maar hadden zij niet het gevoel dat deze ondersteuning wederzijds was. Het overgrote deel van de participanten (90%) gaf aan minimaal één broer of zus in het familienetwerk te hebben. Een kleinere groep (70%) beschouwden hun broers en zussen als belangrijk voor hen. Slechts de helft van de participanten gaf aan een ondersteuningsrelatie met een broer of zus te hebben. Broers en zussen lijken dus iets meer op afstand te staan. Deze bevinding is belangrijk als het gaat om de duurzaamheid van het familiaire steunwerk van mensen met een lichte verstandelijke beperking. Het is immers waarschijnlijk dat ouders niet gedurende het hele leven van hun kind een belangrijke ondersteuningsrol op zich kunnen nemen; oudere ouders zijn mogelijk minder vitaal, ervaren zelf mogelijk meer gezondheidsproblemen en het is waarschijnlijk dat zij eerder zullen overlijden dan hun kind. De betrokkenheid van broers en zussen in het leven van mensen met een lichte verstandelijke beperking kan daarom van groot belang zijn om de duurzaamheid van het netwerk te vergroten. Een andere belangrijke bevinding was dat partners en/of kinderen zelden deel uitmaakten van het netwerk. Mensen met een lichte verstandelijke beperking missen vaak deze potentieel belangrijk bron van sociaal kapitaal. Wanneer participanten wel een partner in hun netwerk hadden, dan werd deze altijd als belangrijk beschouwd.

De participanten in deze studie hadden gemiddeld een gelijk aantal relaties met familie waarin ondersteuning werd ontvangen en gegeven (beide gemiddeld iets meer dan twee). Er bestaan echter grote verschillen binnen de groep participanten als het gaat om het geven van ondersteuning; ongeveer één derde van de participanten gaf aan voor niemand in het netwerk ondersteunend te zijn. Slechts 30% van de familierelaties werd omschreven als wederkerig. De verhouding tussen ontvangen, gegeven en wederkerige ondersteuning varieerde per type familierelatie. Zo waren relaties met partners en vrienden (hoewel deze relaties niet frequent voorkwamen) relatief vaak gebaseerd op wederzijdse ondersteuning (respectievelijk 70 en 65%), terwijl relaties met iets verdere familie (ooms/tante, neven/nichten, grootouders) slechts in 13% van de gevallen wederkerig waren. Dit laatste percentage leek gerelateerd aan het relatief hoge aantal relaties met deze familieleden waarin participanten het gevoel hadden alleen steun te geven. Mensen met een lichte verstandelijke beperking ervaren met name bij te dragen aan het geven van ondersteuning bij deze groep. Echter slechts ongeveer één derde van de participanten includeerde deze relaties in hun netwerk.

Hoofdstuk 5

In de studie van hoofdstuk 5 werd het perspectief van 111 mensen met een lichte verstandelijke beperking (18 – 40 jaar) op hun familienetwerk, vergeleken met het perspectief van hun familieleden (op het netwerk van hun naasten met een lichte verstandelijke beperking; *n* = 111). Tevens werd gekeken of er factoren samenhingen met een eventueel verschil in perspectief op het familienetwerk. Alle participanten werden bevraagd middels de FNM-ID. Ook rapporteerden 111 (persoonlijk) begeleiders over de eventuele emotionele en gedragsproblemen van de participanten met een lichte verstandelijke beperking. De resultaten van deze studie laten zien dat er op een aantal van de netwerkmaten verschillen bestaan in het perspectief van de participanten met een lichte verstandelijke beperking en hun familieleden. Participanten met een lichte verstandelijke beperking en hun familieleden verschilden niet in hun oordeel over de belangrijke netwerkleden en over de steun die mensen met een lichte verstandelijke beperking ontvingen binnen de familie. Echter, familieleden beschouwden mensen met een lichte verstandelijke beperking gemiddeld als minder ondersteunend voor anderen dan dat mensen met een lichte verstandelijke beperking dat zelf deden. Dat resulteerde in minder wederkerige familierelaties voor mensen met een lichte verstandelijke beperking en een minder centrale positie in het netwerk (overbruggend sociaal kapitaal) volgens het oordeel van familie. Ook zagen familieleden minder onderlinge verbindingen tussen alle netwerkleden (verbindend sociaal kapitaal) dan dat de participanten met een lichte verstandelijke beperking aangaven. Kijkend naar factoren die samenhingen met dit verschil in perspectief, dan bleek dat naar mate de persoon met een lichte verstandelijke beperking meer externaliserend gedrag vertoonde, het verschil in oordeel over de ondersteuning die de persoon met de lichte verstandelijke beperking zelf geeft aan anderen groter te worden. Tevens bleek dat vrouwen met een lichte verstandelijke beperking het vaker oneens waren met familieleden over de aanwezigheid van overbruggend sociaal kapitaal. Familieleden zagen mensen met een lichte verstandelijke beperking minder vaak als verbindingsschakel in het netwerk dan dat zij dit zelf zagen en dit gold sterker wanneer de persoon met een lichte verstandelijke beperking een vrouw was.

Hoofdstuk 6

In deze studie werd onderzocht hoe 53 jongvolwassenen met een lichte verstandelijke beperking (18-25 jaar) hun familienetwerk beschreven en werd een vergelijking gemaakt met de beschrijving van het familienetwerk van 53 (mbo-, hbo- en universiteits-) studenten zonder verstandelijke beperking (van hetzelfde geslacht en dezelfde leeftijd).

Alle participanten werden bevraagd middels de FNM-ID. Uit de resultaten bleek dat het sociaal kapitaal binnen de familie verschilde voor de participanten met en zonder verstandelijke beperking. Ten eerste bestonden de familienetwerken van de participanten met een verstandelijke beperking uit minder familieleden alsook uit minder belangrijke familieleden. Meer specifiek noemden zij minder vaak broers/zussen, partners en vrienden als belangrijke netwerkleden. Ook hadden de participanten met een lichte verstandelijke beperking minder relaties waarin zij zowel steun ontvingen als gaven aan familieleden waardoor hun relaties met familieleden minder wederkerig waren dan de familierelaties van de participanten zonder verstandelijke beperking. De resultaten van deze studie laten zien dat jongvolwassenen met een lichte verstandelijke beperking meer afhankelijk blijven van hun biologische familie (d.w.z. het kerngezin) als het gaat om emotionele ondersteuning, dan jongvolwassenen zonder verstandelijke beperking die vaak meer steunende relaties met partners en vrienden ervaren. Daarbij komt dat jongvolwassenen met een lichte verstandelijke beperking zelf een minder ondersteunende rol vervullen voor de leden van het kerngezin (d.w.z. ouders en broers/zussen). Tot slot bleek dat de participanten een gelijk niveau van verbindend sociaal kapitaal, maar een lager niveau van overbruggend sociaal kapitaal ervaarden in vergelijking met de participanten zonder verstandelijke beperking.

Hoofdstuk 7

Tot slot, in de algehele discussie in Hoofdstuk 7, worden de bevindingen van dit proefschrift samengevat en geïntegreerd en de implicaties voor praktijk en beleid besproken.

De overheid heeft steeds meer nadruk gelegd op de informele netwerken van mensen met een verstandelijke beperking. Dit proefschrift laat zien dat de ondersteuningsbronnen binnen de families van mensen met een lichte verstandelijke beperking gemiddeld schaarser zijn dan de bronnen van mensen in de algehele populatie. Omdat hun ondersteuningsbehoeften vaak hoger liggen, kunnen hun families een verhoogde last ervaren en kunnen zij mogelijk niet tegemoetkomen aan de ondersteuningsbehoeften van hun naasten. Professionele ondersteuning blijft mogelijk van groot belang voor veel mensen met een lichte verstandelijke beperking.

Het faciliteren van betekenisvolle sociale relaties met familieleden en belangrijke anderen is een belangrijke rol van professionals. Interventies gericht op het ontwikkelen, versterken en behouden van het informele netwerk van mensen met een lichte verstandelijke beperking kunnen hierbij van groot belang zijn. De overheersende cultuur binnen zorgorganisaties, met name in residentiele voorzieningen, is vaak nog die van 'zorgen voor'. Bestaande netwerkinterventies laten veelbelovende resultaten

zien voor het bevorderen van de participatie en inclusie van mensen met een verstandelijke beperking en het is belangrijk om te kijken hoe deze interventies kunnen worden "opgeschaald" om grotere verschuivingen in (de cultuur van) zorgorganisaties te bewerkstelligen. Het lijkt belangrijk om professionals bewust te maken van de behoeften en wensen van mensen met een lichte verstandelijke beperking op dit gebied en van de rol die zij hebben in het bevorderen van betekenisvolle sociale contacten met anderen. Om positieve relaties met familieleden te bevorderen, zou de focus hierbij kunnen liggen op het bevorderen van wederkerigheid binnen de relatie. Wederkerigheid is een belangrijk aspect van langdurige ondersteunende sociale relaties. Een aantal studies heeft laten zien dat het ervaren van wederkerigheid een positief effect heeft op het welbevinden van naasten. Professionals kunnen de wederzijdse betrokkenheid van hun cliënten en familie mogelijk al op simpele manieren stimuleren, bijvoorbeeld door familie zich welkom te laten voelen in de woning, hun cliënten te stimuleren hen uit te nodigen voor een bezoek en te ondersteunen om berichtjes te schrijven, een kaart te sturen of een cadeau te kopen bij belangrijke gebeurtenissen in het leven van de ander, of hen te ondersteunen om bijvoorbeeld iets leuks te gaan doen met een neefje of nichtje. De resultaten lieten ook zien dat individuele familieleden verschillende perspectieven op het familienetwerk kunnen hebben. Wanneer het familienetwerk actief betrokken wordt in de ondersteuning, is het van belang voor professionals om hier oog voor te hebben en niet alleen de ervaringen van de persoon met de lichte verstandelijke beperking, maar ook de ervaringen en behoeften van de individuele familieleden, in kaart te brengen.

De resultaten binnen dit proefschrift geven tevens aan dat mensen met een lichte verstandelijke beperking moeilijkheden ervaren in het aangaan van relaties met andere mensen in de gemeenschap waar zij wonen. Partners en vrienden maakten zelden deel uit van het netwerk en de participanten in dit onderzoek gaven aan een wens tot meer vrienden en een partner te hebben. Deze relaties kunnen gezelschap, geluk en een verhoogd gevoel van eigenwaarde brengen en kunnen daarmee bijdragen aan de kwaliteit van leven van een persoon. De resultaten lieten zien dat vriendschappen en een romantische relatie een waardevolle bron van wederkerige ondersteuning kunnen zijn. Het is belangrijk om mensen met een lichte verstandelijke beperking te ondersteunen in het aangaan en behouden van deze relaties.

Ook worden in Hoofdstuk 7 een aantal sterktes en beperkingen van de studies besproken. In dit proefschrift werden zowel kwantitatieve als kwalitatieve studies uitgevoerd, waarbij gebruik werd gemaakt van verschillende onderzoeksmethoden (d.w.z. diepte-interviews, gestructureerde interviews, vragenlijsten). De FNM-ID leverde een grote hoeveelheid informatie op over het sociaal kapitaal in de families van mensen met een lichte verstandelijke beperking, met een focus op hun eigen perspectief.

Hoewel er in de kwantitatieve studies gebruik werd gemaakt van een gestratificeerde en at random geselecteerde steekproef, is voorzichtigheid geboden met het generaliseren van de uitkomsten naar de bredere populatie mensen met een lichte verstandelijke beperking; er bestaat een risico op non-response bias. Daarnaast hebben de resultaten betrekking op mensen met een lichte verstandelijke beperking die uitwonend zijn (ouderlijk huis verlaten) en professioneel ondersteund worden vanuit een zorgorganisatie. Ook hadden zij voornamelijk een Westerse culturele achtergrond. Het is belangrijk dat vervolgonderzoek zicht richt op mensen met een lichte verstandelijke die thuis bij familie wonen, niet of nauwelijks professioneel ondersteund worden of een niet-Westerse culturele achtergrond hebben. Dit proefschrift had een focus op emotionele ondersteuning in familienetwerken. Vervolgonderzoek zou ook andere dimensies van familierelaties in kaart kunnen brengen, zoals instrumentele ondersteuning of conflict. Ook is het van belang te onderzoeken hoe de familienetwerken van mensen met een lichte verstandelijke beperking zich over de tijd ontwikkelen en de stabiliteit in kaart te brengen. Als laatste is het belangrijk dat vervolgonderzoek zich richt op ondersteuning in de families van mensen met een ernstigere mate van verstandelijke beperking.

Conclusie

Dit proefschrift laat zien dat sociaal kapitaal een bruikbaar theoretisch kader is om inzicht te krijgen in de familiare ondersteuningsbronnen van mensen met een lichte verstandelijke beperking. Voor onderzoekers en professionals is het van groot belang om een breed perspectief te hanteren bij het betrekken van het netwerk. Het is belangrijk om niet alleen te kijken naar de ondersteuning die mensen met een lichte verstandelijke beperking kunnen ontvangen, maar ook naar wat zij zelf voor de ander kunnen betekenen. Het is van belang voor professionals om een dialoog te starten met zowel mensen met een lichte verstandelijke beperking als hun naasten, om betekenisvolle relaties met belangrijke anderen te stimuleren en sociale inclusie te faciliteren.

Dankwoord (Acknowledgements)
Curriculum Vitae
Publications

Dankwoord (Acknowledgements)

Aan het eind van dit proefschrift is een woord van dank op zijn plaats aan allen die een bijdrage hebben geleverd aan de totstandkoming hiervan.

Allereerst wil ik mijn (co)promotoren prof. dr. Petri Embregts, prof. dr. Richard Hastings en dr. Lex Hendriks bedanken.

Petri, jij bood me de kans om binnen de Academische Werkplaats Leven met een verstandelijke beperking dit promotieonderzoek uit te voeren. Ik ben je enorm dankbaar voor het vertrouwen in mij en de ruimte die je me hebt gegeven om mezelf te ontwikkelen als onderzoeker, maar ook als mens. Ik heb ontzettend veel van je geleerd. Een werkoverleg leidde altijd weer tot nieuwe inzichten. Je was als promotor erg betrokken en voelde altijd haarfijn aan wat er nodig was om ervoor te zorgen dat ik de stip op de horizon bleef zien of deze weer ging zien. Ik heb grote bewondering voor jouw passie voor en visie op de zorg voor mensen met een verstandelijke beperking en kijk uit naar de voortzetting van onze samenwerking. Richard, thank you for all your helpful guidance. Your expertise was very valuable in determining the research topics and the methodology in particular. Your feedback was always thorough and critical, and I have learned a lot from your theoretical, analytical and methodological expertise. Lex, ik kijk met veel plezier terug op onze overleggen in Tilburg of later vaker "in het Nijmeegse". Jij wist altijd de juiste vragen te stellen om de richting van een studie of paper aan te scherpen en de details helder te krijgen. Jouw kijk als methodoloog heeft dit proefschrift beter gemaakt. Bovenal ook veel dank voor je betrokkenheid en de fijne manier van samenwerken.

I would also like to thank prof. dr. Andrew Jahoda for his valuable contribution to this PhD project. Andrew, thank you for all the valuable supervision. I have learned a lot from your insightful feedback, helpful arguments and great expertise in qualitative research, which has been very inspiring to me.

De leden van de promotiecommissie prof. dr. Hedwig van Bakel, prof. dr. Joris Knoben, prof. dr. Dorien Kooij, prof. dr. Geraline Leusink en prof. dr. Bea Maes dank ik voor de tijd en aandacht die zij besteed hebben aan het kritisch lezen en beoordelen van dit proefschrift en hun bereidheid deel te nemen aan de oppositie.

Ik dank Dichterbij voor de kansen die ik heb gekregen om mezelf te ontwikkelen, leidend tot dit promotieonderzoek. Mijn binding met de zorg voor mensen met een verstandelijke beperking begon al in de voedingsdienst, waarna ik de kans kreeg om als begeleider aan de slag te gaan bij Kind en Jeugd. Na heel wat jaren met veel liefde en plezier als begeleider gewerkt te hebben, was het tijd voor een volgende stap en kreeg ik de kans om bij de Academische Werkplaats dit promotieonderzoek te starten.

Zonder de medewerking van alle deelnemers was dit proefschrift er natuurlijk nooit geweest. Ik ben hen dan ook bijzonder dankbaar voor hun openheid en het delen van hun verhaal.
Daarnaast wil ik alle medewerkers van Amarant, ASVZ, Dichterbij, Prisma en Zuidwester die een rol hebben gespeeld in de werving van deelnemers bedanken voor hun hulp en inzet.

Tranzo collega's, bedankt voor de fijne werkomgeving en de gezelligheid tijdens de lunches, het jaarlijkse teamuitje en de heidagen. Van begin af aan heb ik mij welkom gevoeld bij Tranzo, Henk en Dike, dank daarvoor. Ook speciale dank aan alle kamergenoten. Hannah, naast collega van de AWVB, ook mijn vaste kamergenootje. Veel dank voor alle fijne gesprekken over het wel en wee van promoveren, het delen van ideeën over onderzoek, zorg en meer, onze goede theevoorraad, onze schrijfdagen inclusief veel chocolade, je altijd parate kennis en je creativiteit. David, zowel aan het begin als aan het eind van onze promotieonderzoeken zijn we kamergenoten geweest. Bedankt voor alle gezelligheid, het uitwisselen van ideeën en je goede voorbeeld aan Hannah en mij om de chocolade soms ook even te laten staan.

Mijn dank aan alle (oud)collega's van de Academische Werkplaats Leven met een verstandelijke beperking. Wat is het fijn om in dit team te mogen werken. Luciënne, veel dank voor alles wat je in dit promotieonderzoek betekend hebt en voor de fijne samenwerking in de werving van deelnemers, zonder jouw inzet en support was het niet gelukt om de dataverzameling op deze manier uit te zetten en de ruim 400 deelnemers van dit onderzoek te bereiken. Angélique, bedankt voor je geweldige ondersteuning in de dataverzameling. Elsbeth, bedankt voor alle keren dat je bereid was mee te denken of mee te lezen, het werd er altijd beter van. Noud, mijn grote dank voor alle keren dat ik je om hulp heb gevraagd om mee te denken in de opzet van het onderzoek, de analyses en nog veel meer, ik heb er veel van geleerd. Kim, heel erg bedankt voor het zo gedetailleerd nalezen van het gehele manuscript. Moniek, onze fijne gesprekken tijdens de IPA-uren leidden telkens weer tot nieuwe inzichten. Marloes, Lisanne, Anne-Pier, Lex en Marion, bedankt voor alle gezelligheid tijdens de vele treinuren.

En dan mijn paranimfen. Tess, nagenoeg tegelijk begonnen we allebei aan een promotieavontuur en wat was het fijn om in onze onderzoeken samen te kunnen werken. Ik denk met veel plezier terug aan alle keren dat we samen ideeën hebben uitgewerkt, overzichtjes hebben gemaakt, presentaties hebben gegeven en zelfs (ja echt) aan alle uurtjes die we samen achter de computer hebben gezeten voor de netwerkanalyses, wat hebben we toen ook gelachen. Bedankt voor alle gezelligheid en support. Als er iemand alle ins and outs van dit promotietraject kent ben jij het wel en ik ben blij dat je als paranimf achter me staat. Sophie, ik heb je leren kennen als een geweldige collega en kijk met veel plezier (en een beetje heimwee) terug op ons kamergenootschap. Je hebt de dappere stap gemaakt om het onderzoekswerk achter je te laten en ik ben blij voor je dat er mooie nieuwe dingen op je pad zijn gekomen. Bedankt voor de goede gesprekken, je interesse, nuchterheid en humor. En natuurlijk voor het feit dat je mijn paranimf wilt zijn.

Graag bedank ik ook alle andere mensen die zorgden voor de nodige steun, gezelligheid en ontspanning. Annouck, het begon aan het eind van de middelbare school, samen naar concerten geweest (mits de artiest kwam opdagen), een aantal mooie reizen gemaakt en vooral heel veel gelachen. De afgelopen jaren heb ik met jou al mijn lief en (trein)leed gedeeld. Ver weg zal voor onze vriendschap nooit te ver zijn. Mariëlle, al heel lang mijn lieve vriendinnetje. We hebben al veel meegemaakt samen en heel wat plezier beleefd de afgelopen jaren. Ik wil je bedanken dat je zo met me hebt meegeleefd in dit promotietraject. Iris, we kennen elkaar al ons hele leven, ik heb heel wat uurtjes bij jullie thuis doorgebracht. Ook al zien we elkaar nu niet altijd even vaak, we weten precies wat we aan elkaar hebben en dat waardeer ik enorm. Sanne, Maartje, en Mirthe (de Optimisten), hoewel de naam van onze groepsapp is ontstaan tijdens het kijken van een potje voetbal aan het Koningsplein, is hij typerend gebleven. Bedankt voor alle support en gezelligheid. Angèle, hetzelfde studiepad doorlopen, maar we leerden elkaar pas echt kennen tijdens de research master. Bedankt voor alle goede gesprekken de afgelopen jaren tijdens een lunch of een ontspandagje. Marissa, al onze wandelingetjes met fijne gesprekken zijn heel waardevol geweest. Leon, we hebben elkaar leren kennen in Cusco, maar ook in Nederland hebben we nog altijd genoeg te bespreken tijdens een lunch of etentje. Bedankt voor al je interesse in dit proefschrift. Tobias and Beatrice, thank you for all the fun and great experiences that we have shared during our trips.

En dan mijn eigen familie. Anny en Reen, mijn lieve peettantes, bedankt voor al jullie betrokkenheid in mijn leven. Saskia, in herinnering, wat keek ik altijd op tegen mijn 'grote' nicht en wat had ik je graag dit proefschrift laten zien. Erica, bedankt voor alle fijne gesprekken aan de keukentafel, met een kop thee of een lekkere lunch. Co en Ria,

bedankt voor al jullie interesse. Jaap en Dinie, bedankt dat jullie altijd voor ons klaarstaan.

Lieve pap en mam, bij jullie ligt mijn basis. Bedankt voor jullie liefde, vertrouwen, en onvoorwaardelijke steun in alles wat ik doe en de keuzes die ik maak. Het is zo fijn altijd bij jullie terecht te kunnen. Rick, bedankt voor jouw hulp en steun wanneer het nodig is. We delen onze liefde voor dieren en fotografie en het is fijn om jou als broer te hebben.

Als laatste, lieve Allan, samen is alles leuker (en met Ori erbij natuurlijk, ons lieve en vrolijke Sta-me-bijtje). Bedankt dat je er altijd voor me bent, dat ik alles met je kan delen en dat je me de rust en ruimte hebt gegeven om dit proefschrift te kunnen schrijven. Ik ben blij dat we samen zijn.

Curriculum Vitae

Sanne Giesbers werd op 11 november 1987 geboren te Nijmegen. In 2006 behaalde zij aan het Elzendaal College te Boxmeer haar VWO diploma. Vervolgens ging zij Pedagogische Wetenschappen en Onderwijskunde studeren aan de Radboud Universiteit te Nijmegen, waar zij in 2009 haar bachelordiploma cum laude behaalde. In 2011 voltooide zij de research master Behavioural Science (cum laude) en in 2012 behaalde zij de master Orthopedagogiek: Leren en Ontwikkeling. Van 2005 tot en met 2014 heeft zij binnen een aantal woonvoorzieningen van Dichterbij als begeleider van kinderen en jongeren met een verstandelijke beperking en moeilijk verstaanbaar gedrag gewerkt. Vanaf april 2014 liep dit over in een aanstelling als promovenda bij Dichterbij Behandelinnovatie en Wetenschap en was zij vanuit deze aanstelling verbonden aan de Academische Werkplaats Leven met een verstandelijke beperking (Tranzo, Tilburg University), waar zij onder begeleiding van prof. dr. P. J. C. M. Embregts (Tilburg University), dr. A. H. C. Hendriks (Radboud Universiteit) en prof. dr. R. P. Hastings (University of Warwick, VK) haar promotieonderzoek heeft uitgevoerd. Momenteel werkt zij als postdoc onderzoeker bij de Academische Werkplaats Leven met een verstandelijke beperking, Tranzo, Tilburg University.

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It’s not who you know, It’s how you know them

Support in formal and informal networks of people with mild intellectual disability